

**Trauma-Informed Care for Young People with Intellectual Disabilities:  
Perspectives of Residential Support Workers**

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## **ABSTRACT**

**Background:** The long term, serious impact of trauma on health and wellbeing has been extensively researched in the general population, however, it is only recently that people with intellectual disabilities have begun to be represented in trauma literature and very few studies have considered young people with intellectual disabilities specifically. Young people with intellectual disabilities are more likely to experience trauma, compared to the general population and those living in residential care are particularly at risk. Evidence of the need for multi-systemic, trauma-focussed intervention has been provided. Residential support workers make up a key part of the system around young people with intellectual disabilities in residential care and accessing their views and experiences may be crucial for the development and implementation of trauma-focussed initiatives.

**Aims:** This research aimed to explore how residential support workers understand and respond to trauma in young people with intellectual disabilities, alongside barriers and facilitators to support, with view to understanding how to upskill services in trauma-informed practice.

**Method:** Semi-structured interviews took place with ten residential support workers from nine organisations, eight were recruited via social media and two through their organisation. Participants were two males and eight females, and experience ranged from 1.8 to 15 years. Reflexive Thematic Analysis was employed.

**Results:** Analysis generated three themes: 'Trauma in the system', 'Recognising, Responding and Resistance to Trauma' and 'More Than a Job', within which nine subthemes were generated.

**Conclusions:** Residential support workers of young people with intellectual disabilities described working within a system which causes and perpetuates harm at various levels. They demonstrate a broad knowledge of the prevalence and impact of trauma on this population and described a particular focus on

attachment as key for the young people they support. Findings highlighted the need for staff support, trauma-focussed training, and systemic change, including the consideration of trauma-informed care by residential organisations, intellectual disability services and within policy.

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## **ACRONYMS**

RSW – Residential Support Worker

YPWID – Young People with Intellectual Disabilities

ID- Intellectual Disabilities

PWID – People with Intellectual Disabilities

ACEs – Adverse Childhood Experiences

PTSD – Post Traumatic Stress Disorder

EMDR – Eye Movement Desensitisation and Reprocessing

CBT – Cognitive Behaviour Therapy

PBS – Positive Behaviour Support

TIC – Trauma Informed Care

TA- Thematic Analysis

Organisations/Policies:

SAMHSA - Substance Abuse and Mental Health Administration

DSM-5 – Diagnostic Standards Manual – 5

ICD-11 – International Classification of Diseases- 11

AAIDD- American Association on Intellectual Disabilities

APA – American Psychological Association

WHO – World Health Organisation

BPS – British Psychological Society

DCP – Division of Clinical Psychology

CDC – Council for Disabled Children

LeDeR – Learning from deaths – people with a learning disability and autistic people

STOMP- Stopping the Over-Medication of People With Intellectual Disability, Autism or Both

STAMP- Supporting Treatment and Appropriate Medication in Paediatrics

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

DoH- Department of Health

DfE – Department for Education

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## 1. INTRODUCTION

This thesis examines how residential support workers (RSW) of young people with intellectual disabilities (YPWID) understand and respond to the impact of trauma and adversity amongst those they support and explores their experience of this work.

This chapter presents a narrative review of the literature on the meaning and construction of intellectual disability (ID), the concept of trauma and its relevance within this population, and current pertinent issues and policy. It describes the significant role of residential services and RSWs in the lives of YPWID, presenting the results of a scoping review aimed at understanding what is known about RSW's and other stakeholders' perspectives on supporting people with intellectual disability (PWID) who have experienced trauma.

Traditionally, research on trauma, ID and child populations have been compartmentalised through discipline specific approaches and associated terminologies, creating challenges in generating and accessing accumulative knowledge (Cook & Hole, 2021). The narrative and scoping review draws on literature focussed on child and young person ID populations where possible, alongside literature based in adult ID populations (age over 18), and in child populations which do not specify ID.

The Children and Families Act (2014) established provisions for YPWID, including Education, Health and Care plans. Notably, this legislation extended the local authority's responsibilities up to age 25, to aid transition to adult services. This review considers research on children and young people from birth to age 25, with a diagnosed or suspected ID, whilst the research project focuses on those aged 12-25.

The term 'intellectual disabilities' (ID) is now most frequently used within international literature and is being increasingly adopted within UK literature. For the sake of clarity, this term will be used throughout this thesis.



## 1.1. Defining Intellectual Disability

'ID' incorporates people with a range of abilities and needs. Three major diagnostic manuals, (Diagnostic Standards Manual [DSM]-5, International Classification of Diseases [ICD]-11 and American Association on Intellectual Disabilities [AAIDD]-12) define ID based on limitations of intellectual ability and adaptive functioning, present during the developmental period (American Association on Intellectual Disabilities [AAID], 2021; American Psychological Association [APA], 2013; World Health Organisation [WHO], 2018). Based on these manuals, the British Psychological Society's Division of Clinical Psychology (BPS DCP) provides guidance on the assessment and diagnosis of ID (DCP, 2015). All three systems identify that limited intellectual ability is indicated by an IQ of 70-75 or below on standardised psychometric testing. Beyond this ID can be categorised as mild, moderate, severe or profound, based on measures of intellectual and adaptive functioning and support needs (AAIDD, 2021; APA, 2013; WHO, 2018).

### 1.1.1. Issues With Definition and Diagnosis

The use of intelligence testing in diagnosing ID has been criticised for its inaccuracy, particularly when measuring within low ranges, with measured intelligence often differing from true intellectual ability (Whitaker, 2013). 'Adaptive functioning', concerns conceptual, social and practical skills and activities of daily life, measured using norm-based standardised assessment (DCP, 2015). This concept has been criticised as lacking a theoretical framework, with definitions largely based on what assessment tools measure, showing little consideration of cultural context (Harris & Greenspan, 2016; Price et al., 2018; Whitaker, 2013). Additionally, Whitaker (2013), notes that measures are prone to error, floor effects and inconsistencies between tests and between responders (2013).

A conceptual challenge for this research is that ID is not always diagnosed in childhood. Children who show delays in meeting developmental milestones can be referred for professional assessment, which considers the significance and degree of delay, social and educational needs. They may be formally assessed and diagnosed at this stage, or re-evaluated in later childhood, adolescence or

adulthood (Carr et al., 2016). Although developmental concerns are often identified in early childhood, many young people do not receive official diagnosis, particularly if the ID is mild or if the social or environmental context means difficulties are unproblematic until circumstances change (Delahunty et al., 2022). When developmental delay is indicated but level of impairment is unclear, a diagnosis of Disorder of Intellectual Development may be given (WHO, 2022).

Whilst the DSM-5 and ICD-11 define ID as a disorder, the latest manual from the AAIDD conceives it as a state of functioning resulting from discrepancy between an individual's abilities and their social and physical environment (AAIDD, 2021), marking a shift away from dominant medicalised conceptualisations of ID, towards a socially contextualised understanding.

#### 1.1.2. Social Construction of Intellectual Disability

The construct of ID can be traced to the construction of disability (Schalock, 2011). Historically, in western culture, a medicalised approach has conceptualised disability as an individual deficit, focusing on impairment and pathology and emphasising diagnosis and treatment (Oliver & Barnes, 2012). The medicalisation of disability has contributed to negative stereotypes, provided justification for discriminatory practices and positioned people with disabilities as dependent upon medical diagnosis and treatment (Barnes, 2020; Oliver & Barnes, 2012).

A social-ecological conception of disability began with the emergence of disability studies in the 1980's, leading to an increased understanding of the process of disablement as routed in barriers imposed by the physical and social environment (Barnes, 2020). This 'Social Model' contains a focus on empowerment and self-determination, creating an awareness of marginalisation and discrimination through the separation of impairment and disabling barriers (Oliver, 2013). This shift in understanding led to the conceptualisation of disability as a human rights concern, giving rise to multiple legislative measures to address the economic and social barriers disabled people face. However, these changes have been largely unsuccessful in changing the lived reality of disabled people (Barnes, 2020).

The Social Model has been critiqued for not explicitly considering PWID and there is some debate around how well it accounts for their specific experiences (Goodley, 2001). Whilst capitalism, industrialisation, medicalisation, exclusion and discrimination can apply to all disabled people (Stalker, 2020), it has been argued that PWID face additional barriers in terms of societal attitudes, are at greater risk of abuse and neglect and face additional barriers in terms of accessibility of information (Aspis, 1999; Chappell, 1998; Stalker & Lerpiniere, 2009). Researchers have called for a focus on the needs of PWID through involving them in research and improving the accessibility of critical disabilities studies (Boxall, 2006). Despite such debates, a social-ecological understanding of ID has emphasised the impact of individualised supports in improving functioning, also shining light on systems of power and oppression which impact the everyday lives of PWID (Schalock, 2011).

## **1.2. Trauma**

In this thesis the term 'Trauma' will be used in line with the Substance Abuse and Mental Health Administrations (SAMHSA, 2014, p.7), definition:

*"Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being."*

Psychological trauma is commonly defined as either single incident trauma or complex/developmental trauma (e.g. abusive or threatening conditions experienced over time), although these terms are not mutually exclusive (Reed et al., 2016). In this thesis the term 'trauma' will be used to describe both categories. This research is specifically concerned with the impact of trauma on children and young people, known as 'childhood trauma'.

Whilst various psychological models will be described later with their relevance to YPWID, a socio-ecological perspective describes how early adverse experiences shape development. Bronfenbrenner (1979) described five ecological systems influencing childhood development. Disruptions within these systems, including a spectrum of stressors and trauma, can impact health, wellbeing and development with consequences observable in adulthood. This model highlights experiences beyond individual and family based adversity, including broader community (e.g. neighbourhood deprivation, community violence), and societal factors (e.g. discrimination, social inequality) (Lopez et al., 2021).

This research will refer to trauma as that which occurs at the individual, inter-personal and wider societal level, considering anything which might be experienced as deeply adverse and stressful.

#### 1.2.1. Adverse Childhood Experiences

Research often refers to experiences of adversity and trauma in childhood as adverse childhood experiences (ACEs) (Ellis & Dietz, 2017). The term was popularised by Feletti et al (1998), who's research explored the impact of childhood adversity throughout the life course. Varying definitions and traditions have arisen in the ACEs literature, Young Minds (2018, p.28) have produced a definition of ACEs to reflect this:

*Adverse childhood experiences are highly stressful and potentially traumatic events or situations that occur during childhood and/or adolescence. It can be a single event, or prolonged threats to (and breaches of) the young person's safety, security, trust or bodily integrity. These experiences directly affect the young person and their environment, and require significant social, emotional, neurobiological, psychological or behavioural adaptation.*

The original ACEs framework involved ten events, however researchers have recommended the addition of various other adverse experiences based on empirical evidence (Afifi, 2020). These include; poverty, sibling violence, bullying, peer rejection and community violence (Finkelhor et al., 2015), attachment-related events such as entry to the care system, separation from

parents and parental death and discrimination based on race, sexual orientation, religion or disability (Burke Harris & Renschler, 2015).

ACEs research has highlighted that ACEs are highly prevalent in the general population and across cultures (Ports et al., 2020). Research has linked ACEs to a heightened risk of adverse physical and mental health outcomes (Felitti et al., 1998; Gilbert et al., 2015; Herzog & Schmahl, 2018) and limitations in life opportunities, such as educational achievement and employment (Metzler et al., 2017). There is evidence that ACEs have an accumulative effect (Hughes et al., 2017). However, ACEs research has been critiqued for not considering dimensions such as culture, age, chronicity and severity (Afifi, 2020). It is therefore important to avoid a focus on ACEs, to the exclusion of other forms of childhood adversity and the diverse ways children respond to these experiences (Bartlett & Sacks, 2019). This thesis will consider both trauma and ACEs literature together.

### **1.3. Trauma, ACE's and PWID**

Although trauma and ACE's have been extensively studied in the general population, representation of the experiences of PWID in this literature is relatively recent (Rittmannsberger et al., 2019).

#### **1.3.1. Prevalence**

YPWID are more likely to experience adverse and traumatic experiences compared to the general population. A large population based study in the UK investigated recorded cases of childhood abuse and neglect, finding children with moderate to severe ID were at an increased risk of experiencing emotional, physical and sexual abuse and neglect (Spencer et al., 2005), with similar findings documented internationally (Dion et al., 2018; Maclean et al., 2017; Sullivan & Knutson, 2000). In the US researchers found that children with developmental disabilities were more likely to experience ACEs, regardless of socio-economic status (Berg et al., 2019). A systematic review and meta-analysis found that YPWID are at greater risk of experiencing violence than children with other types of disability (Jones et al., 2012). There have been many factors associated with increased abuse and neglect of YPWID, including

discriminatory societal attitudes and assumptions, dependency on large networks of carers and supporters, communication barriers meaning YPWID are less able to report abuse, difficulty interpreting behaviours and family isolation (Murray & Osborne, 2009).

It is important to consider that prevalence data on abuse and neglect are based on reported cases, yet there is evidence that many YPWID who are maltreated are not identified, due to the tendency of services to dismiss abuse of disabled children (Cooke & Standen, 2002). There has been limited research exploring the impact of wider systemic trauma which PWID commonly face, for example related to discrimination and low socio economic status (McNally et al., 2021). A further issue is that the threshold for what is experienced as traumatic may be lower in PWID (McCarthy et al., 2017), and research has linked common life events such as moving school, or ongoing minor adversities such as failure and rejection to the development of traumatic stress (Levitas & Gilson, 2001; Mevissen & De Jongh, 2010), meaning traumatic experiences for YPWID may be underreported.

### 1.3.2. Mechanisms of Trauma in YPWID

Various psychological models suggest mechanisms of the impact of childhood trauma in the general population, these will be described alongside their relevance to YPWID.

1.3.2.1. Attachment model: This approach proposes that early caregiver relationships establish foundational internal working models, supporting long-term social, cognitive and emotional development and emotion regulation, through the internalisation of affective caregiver interactions (Ainsworth, 1978; Tronick et al., 1977). In an environment where caregivers are perceived as dangerous, unresponsive or unpredictable children may develop attachment styles associated with emotional, behavioural and relational difficulties, and use strategies such as withdrawal, aggression or dissociation for regulation (Lyons-Ruth et al., 2009; Ringel, 2014). The British Psychological Society, (2017) acknowledged the common occurrence of attachment disruption in YPWID. In some cases parents may find it harder to read and respond to their child's emotional signals, whilst distress related to ID diagnosis may mean parents are

less likely to respond with behaviours that promote security (Schuengel et al., 2013; Schuengel & Janssen, 2006). YPWID are likely to receive support from a variety of services, posing risk for attachment disruption due to discontinuity in staff, and immersion in service cultures which often promote independence, rather than the interdependence valued in the attachment literature (BPS, 2017). YPWID may also be more likely to experience 'fright without solution' due to a reduced ability to independently manage emotional stressors, and a potential lack of available attachment figure to support regulation (Schuengel & Janssen, 2006). Lyons-Ruth et al, (2009) describe that children who experience maltreatment, deprivation of care or who are raised outside of the home may demonstrate specific difficulties forming stable relationships. A move to residential care may represent a significant disruption in attachment for YPWID and provide opportunity for further disruption in relationships as staff change or move on.

1.3.2.2. Discrimination and social inequality: The socio-ecological model highlights links between social inequality and trauma (Lopez et al., 2021). PWID have been subject to severe and violent discrimination in many areas of life throughout history (Joint Committee on Human Rights, 2008; Oliver & Barnes, 2012), often related to misconceptions around their capability or fear and discomfort around interaction (Scior & Werner, 2015). PWID report that discrimination affects their daily lives, including in access to employment, leisure, education and through experiences of harassment and peer rejection (Buljevac et al., 2022; Scior & Werner, 2015). YPWID often experience high rates of victimisation by peers (Maïano et al., 2016), and encounter discrimination within the education system, driving social isolation (O'Byrne & Muldoon, 2019). Discrimination can affect the families of YPWID, who are more likely to experience socioeconomic adversity, lack of family support and negative community attitudes, increasing parental stress and risk of social withdrawal (Algood et al., 2011; Berg et al., 2019; Mitter et al., 2019; Scior & Werner, 2015) with implications for increased safeguarding risk (Murray & Osborne, 2009).

Discrimination of YPWID has been identified within the healthcare system, including poor staff understanding of ID, failure to recognise illness or pain, poor

inter-agency collaboration and poor service provision (Allerton & Emerson, 2012; Heslop et al., 2014; Tuffrey-Wijne et al., 2013). Diagnostic overshadowing describes the tendency of health professionals to attribute symptoms to being part of an individual's ID, this is common in terms of mental health difficulties and has impact for diagnosis, and the types of support provided to PWID when experiencing distress (Mason & Scior, 2004). Emerson (2015), provides a review of consistent, international evidence that YPWID are at increased risk of all social determinants of poor mental and physical health, this may be demonstrated in statistics confirming that YPWID are four times more likely to develop a mental health problem than children in the general population (Rainer & Abdinasir, 2023). Whilst inequality should be addressed irrespective of age, evidence suggests an emphasis on interventions during childhood can be particularly advantageous for promoting long term health and wellbeing outcomes (Marmot et al., 2008, 2020; WHO, 2014, 2018).

1.3.2.3. Cognitive model: A key cognitive model of trauma is rooted in emotional-processing theory, which suggests that the emotion and meaning attached to traumatic experiences results in them not being processed like other memories (Foa & Kozak, 1986). Ehlers & Clarke (2000) describe that inadequate processing and integration of trauma memories within context leads to a sense of current threat, resulting in involuntary intrusive memories or re-experiencing. Some research has suggested that cognitive impairment can increase susceptibility to the negative impact of trauma exposure, with reduced cognitive mechanisms to process and cope with adverse events linked with the development of post-traumatic stress disorder (PTSD; Martorell et al., 2009). Delhalle & Blavier (2023), found lower intellectual ability was associated with increased PTSD symptoms in children, linked with decreased verbal comprehension skills. It was hypothesised that verbal abilities support the consolidation of traumatic memory, through contextual integration into personal narratives, also enabling problem-based coping strategies and access to social support. This evidence suggests YPWID may be particularly at risk for the development of severe and enduring psychological difficulties related to experience of trauma.



1.3.2.4. Neurodevelopmental model: This perspective describes that early maltreatment can biologically alter brain structure and function, producing a brain focussed on survival. This is characterised by enhanced stress responsiveness alongside reduced capacity for emotion regulation and development of secure, trusting relationships (Greene et al., 2014; Herringa, 2017; Teicher et al., 2002). Prolonged overwhelm of the bodies stress response, may diminish the individuals ability to cope with environmental demands, leading to physical and emotional problems throughout life (Juster et al., 2010). Social engagement has been described as a mediating factor, which can assist in regulation, or exacerbate the survival response (Tucci et al., 2018). Sheridan & McLaughlin (2020) describe how deprivation of social and cognitive stimulation and learning opportunities causes early and excessive synaptic pruning, producing a neural system unable to cope with a complex environment, with implications for cognitive development, particularly in areas of language and executive functioning. Whilst the overlap between the cognitive impact of neurodevelopmental trauma and ID is complex (Woods & Freedman, 2015) this model suggests that early trauma may exacerbate cognitive, adaptive and relational difficulties in YPWID.

### 1.3.3. Presentation of Trauma

1.3.3.1. Psychological Distress: Research has linked psychological health problems with experience of childhood trauma in PWID, evidencing a cumulative effect (Catani & Sossalla, 2015). The majority of research in trauma and ID has focussed on understanding differences in trauma related symptomology between adults with ID and the general population, with findings suggesting the mental and social impact of trauma is broadly similar (McNally et al., 2021). Trauma and stress related disorders in PWID are outlined in the DSM-5 and it's companion, the Diagnostic Manual-ID (Fletcher et al., 2016). PTSD in people with mild ID is described as similar to the general population, in that they appear to experience intrusive thoughts, nightmares and intense, prolonged emotional distress, though trauma may manifest behaviourally in people with severe ID (McCarthy et al., 2017). Emerson & Hatton (2007), described that social disadvantage was related to increased prevalence of all mental health diagnoses in YPWID.

A small number of studies have described the psychological impact of trauma from the perspective of individuals with ID. Stathopoulou et al (2018), surveyed YPWID who reported trauma, participants described fear of negative thoughts and of school, a preference for isolation and feelings of inferiority, embarrassment, unhappiness and suicidal ideation. Other literature has described the lasting impact of childhood trauma. Wilczek (2021) provided a personal account of his experience of childhood trauma, reporting links with mental health difficulties into adulthood, including severe low mood, anxiety, suicidality and the re-experiencing of traumatic events when faced with new stressors. Mitchell et al, (2006) interviewed six adults with ID who had experienced trauma in childhood and adulthood, participants described a prolonged sense of danger, self-blame, experiences of intrusive mental images and avoidance of thoughts and reminders of their trauma.

1.3.3.2. Behaviour: Research suggests that trauma is likely to manifest in the behaviours of PWID (McNally et al., 2021). The conceptualisation of behaviour in ID is complex, a brief description of 'challenging behaviour' will be provided, followed by its relevance to trauma.

'Challenging behaviour' refers to behaviours which challenge services. Emerson (2001) describes these as behaviours which deviate from cultural norms, endanger the physical safety of the self or others, and may result in exclusion from community facilities. Such behaviours are common and highly impactful in the life's of PWID, their families and carers, and can influence families to seek out residential care placement for their child (Gore et al., 2022; Llewellyn et al., 2005). Children and adults with ID who display challenging behaviour are also more likely to be detained in institutional settings (Emerson, 2011). Challenging behaviour is a social construction, what is defined as challenging varies dependent on context, social rules defining the appropriateness of behaviours in a particular setting, the ability of the individual to justify their behaviour, the beliefs held by others about the cause of the behaviour and the capacity of the setting to manage disruption resulting from the behaviour (Emerson, 2011).

Harding (2021) described how a range of behaviours associated with trauma in the general population might be observed as 'challenging' in PWID. In YPWID

manifestation of PTSD symptoms may be observed through re-enactment, sudden episodes of aggression or self-harm, inability to calm down and reactive behaviour (Kildahl et al., 2020a). In people with severe ID, signs of PTSD are thought to include re-enactment of trauma, aggression, anxious interactions and fearfulness in new relationships (McCarthy et al., 2017). However research has also described that some individuals with severe ID may exhibit prolonged reduction in behaviours in response to trauma (Murphy et al., 2007; Rowsell et al., 2013). Trauma related behaviours have the potential for criminalisation and institutionalisation of YPWID. Emerson & Hatton (2007) found that exposure to social disadvantage was related to conduct disorder in YPWID and Morris et al. (2020) has described a pathway from childhood adversity into secure care in adolescence.

1.3.3.3. Health: ACEs literature has documented links with negative health outcomes across the lifespan (Felitti et al., 1998). PWID experience disproportionate levels of adversity (Berg et al., 2019), and in the UK their health outcomes and life expectancy are reduced compared to the general population, with recent reports finding almost half of deaths of PWID were avoidable (LeDeR, 2022). Direct exposure to disablism along with exposure to poor living conditions produced by discriminatory systems, are associated with poor outcomes in mental and physical health (Emerson & Gone, 2012), whilst multiple disparities in healthcare have been linked to a range of long term health outcomes (Krahn et al., 2006).

#### 1.3.4. Trauma Focussed Interventions

There is currently no validated tool to assess trauma experiences of PWID and they are less often considered for trauma-focussed interventions, however, recent research has piloted adapted interventions recommended for the treatment of PTSD (NICE, 2018) such as Eye Movement Desensitisation and Reprocessing (EMDR) and trauma focussed Cognitive Behavioural Therapy (CBT) (McNally et al., 2021). Other clinicians have sought to integrate a trauma-focus into interventions commonly used to support PWID:

1.3.4.1. Positive Behaviour Support (PBS): This describes a person-centred framework for providing support to PWID and/or Autism who display challenging

behaviour. It comprises functional assessment of the behaviour and co-production of care plans which promote preventative strategies (BILD et al., 2017). Harding (2021), describe how trauma focussed PBS can be provided through attention to relational security, functional analysis which looks beyond short-term functions of behaviours, to understand them within the context of adaptation or coping, behavioural strategies which focus on security, attunement and co-regulation and crisis planning which promotes emotional security.

1.3.4.2. Intensive Interaction: This describes a tool used to enhance the communication and social skills of people with severe ID, who may be unable to communicate verbally, through building on their natural communication style in a supportive and engaging way (Hewett et al., 2015). Samuel & Doswell (2021), Intensive Interaction's emphasis on attachment development and empowerment aligns with trauma-focussed models. They propose an increasingly trauma-focussed adaptation of the approach which incorporates trauma assessment, creates shared trauma-focused formulations, and guides supporters in using intensive interaction strategies to promote rapport, trust, and security. Safe implementation of this approach requires services to support staff wellbeing and knowledge through reflective practice.

1.3.4.3. Trauma Informed Care: As PWID often rely on various services for support, there has been recognition of the need for a systems-focussed approach for supporting trauma in ID organisations (Goad, 2021; Keesler, 2014a; McNally et al., 2023). Trauma informed care (TIC) is a framework for service delivery, developed for use in the general population. The Substance Abuse and Mental Health Administration (SAMHSA, 2014) describe four assumptions which support TIC:

- Realise: All staff have a basic understanding of trauma and how it affects individuals and systems.
- Recognise: All staff can recognise signs of trauma.
- Respond: The organisation responds to trauma appropriately.
- Resist Re-traumatisation: The organisation resists the re-traumatisation of all clients and staff

Reviews have described positive outcomes in the implementation of TIC in various children's services including social care, health, education and youth justice settings (Bryson et al., 2017; Bunting et al., 2019). The Scottish Government (2023), conducted an evidence review, describing that TIC improved staff wellbeing and confidence, enhanced inter-agency collaboration, reduced emotional difficulties and increased functioning in children.

ID services have begun to implement TIC, however research has described various challenges, including gaps in knowledge of service providers, high staff turnover, lack of training and unsupportive organisational culture (Keesler, 2014a, 2016, 2020; Rich et al., 2021). Goad (2021) describes how resistance to TIC can occur at the individual and organisational level. Staff may experience emotional challenges when engaging with the trauma experiences of clients and their related distress, potentially leading to minimisation or avoidance of acknowledging trauma. Staff's own attachment styles might interact with those of the people they support, and they may feel ill-equipped to meet the complex needs of PWID who have experienced trauma. At the organisational level Goad describes how priorities, such as financial deficits and target driven practices, can develop a "threat-filled" culture which supersedes compassion. McNally et al. (2023), describes the importance of involving all stakeholders in the development of TIC initiatives, co-producing adapted principles for implementing TIC within adult ID residential services, comprising; Safety, Trustworthiness, Choice and Voice, Collaboration and Mutuality and Empowerment.

#### 1.3.5. Relevant Policy

There have been calls for the development of community capability in meeting the needs of PWID whose behaviour challenges (McGill et al., 2020) and Parliamentary enquiries have emphasised that community ID services need to consider the impact of trauma (Health and Social Care Committee, 2021). Recognition of trauma's prevalence and impact could enhance services ability to support YPWID, through changing the way behaviour is interpreted and supported and reducing the risk of re-traumatisation within services. This is relevant in UK policy.

1.3.5.1. Reducing inpatient care: In 2011 BBC Panorama exposed abuse at Winterbourne View, a hospital for PWID and autism. Subsequent inspections reported severe inadequacies in many hospitals and residential services for PWID and autism (Parkin, 2023). In response, the Department of Health (DoH) published the 'Transforming Care' Agenda which set out to transform services for PWID or autism, mental health difficulties and challenging behaviour. This involved a pledge to review all current hospital placements and move inappropriately hospitalised PWID into community-based care by June 2014 (DoH, 2012). This target was missed as the government underestimated the complexity of achieving this plan and had failed to consider the ability of local commissioners to provide adequate community placements and care plans (National Audit Office, 2015; Transforming Care and Commissioning Steering Group, 2014).

This starkly highlighted a need to increase specialist community provision to allow for safe discharge, and early intervention in the community to prevent admission (DOH, 2015; Transforming Care and Commissioning Steering Group, 2014). In 2015 the 'Building the Right Support' plan, detailed aims of reducing the use of inpatient facilities for PWID and autism who display behaviour that challenges by 2018, shifting funding to community services (NHS England, 2015). The NHS Long Term plan produced an extended deadline to achieve a 50% reduction in hospital placements by 2023/2024 (NHS, 2019). However, data at this time indicated large numbers of PWID were still detained and subject to frequent physical restraint (NHS Digital, 2019).

The marked failure of the government to fulfil the aims initially set out in the Transforming Care agenda has been described as a human rights scandal (Mencap, 2019), resulting in a legal challenge by The Equality and Human Rights Commission (Parkin, 2023). The Department of Health and Social Care (DoHSC, 2022) updated the 'Building the Right Support Plan', with six areas for development, including ensuring PWID and autism's access to quality health and social care in mental health settings and adequate community support. Recent data suggests that PWID in inpatient settings continue to receive poor

care, remain subject to high levels of restrictive practice and often do not have needs that necessitate hospitalisation (NHS England, 2022).

1.3.5.2. Stopping the Over-Medication of PWID, Autism or Both (STOMP) and Supporting Treatment and Appropriate Medication in Paediatrics (STAMP): Concern around the over-prescription of psychotropic medication to PWID has persisted since the 1970's (Branford et al., 2019b). Controversially, its use in the absence of psychiatric diagnosis has been noted in the treatment of challenging behaviour (Levitas & Hurley, 2006), despite lack of evidence for its efficacy (Tyrer et al., 2008). The case review of Winterbourne View and further reports from NHS England highlighted that PWID and autism were subject to disproportionate levels of treatment with psychotropic medication (DoH, 2012; PHE, 2015; Slowie & Ridge, 2015). In response, NHS England issued a call for action, resulting in the creation of the STOMP programme, a three year initiative developed to reduce over-medication and support withdrawal (Branford et al., 2019b, 2019a). Whilst STOMP focussed on overmedication in adults with ID, overmedication in YPWID was also evident and in 2018 NHS England and the Royal College of Paediatrics and Child Health launched STOMP-STAMP, producing a pledge and a set of principles to reduce the overmedication of YPWID (NHS England, 2019a, 2019b).

The NHS Long Term Plan has committed to expanding STOMP-STAMP, through raising awareness and initiatives to reduce prescribing (NHS, 2019). However, a review in 2022 suggested that rates of prescription remain high compared to the general population (Branford & Wilcock, 2022). A concern is that medication is used to treat symptoms (e.g. challenging behaviour), neglecting to investigate or treat the root cause, which could be related to a range of bio-psycho-social factors. When medication is reduced behaviours can return, leading to long-term and inappropriate use of medication (Swanepoel & Lovell, 2023), evidencing the need for programmes which provide alternative interventions and consider underlying causes of challenging behaviour (Branford & Wilcock, 2022).

#### **1.4. Residential Services**

Children's residential care refers to group care provided by teams of paid staff, organised through a care order or on a voluntary basis (Strijbosch et al., 2015). There are issues analysing the data of the YPWID population who live in out of home care in the UK (Hill et al., 2017). In England disability is only recorded if it is the main reason a young person is not living with their family and type of disability is not specified. If a child has been subject to abuse or neglect this is recorded as their primary need, so numbers of YPWID in the care system are likely to be vastly under-represented (Council for Disabled Children, 2015). Though more robust datasets are produced in the rest of the UK, issues with defining both disability and care-experienced children present challenges for collating and analysing data nationally (Hill et al., 2017).

The Council for Disabled Children (CDC, 2015), reported that those who were recorded as being in care with disability as their main need were five times more likely to be in a residential placements compared to all care-experienced children, with the majority living in children's homes or residential schools. Most entered when they were older than 10 years of age, with the majority of residential placements occurring during secondary school age. Most disabled children represented in this data were under a voluntary agreement and were more likely to be placed outside local authority boundaries, with many living a significant distance from home.

#### 1.4.1. Models of Care

'Normalisation' ideology influenced service development in the 1970s, with a shift away from institutionalisation of PWID. The aim was to support PWID to live 'normal' lives; it was criticised for leading to the development of inadequate community provision which required PWID to 'fit in' without adjustments (Jackson & Irvine, 2013; Michael & Richardson, 2008). Furthermore, it's focus on autonomy legitimised the authority of professionals in developing services and teaching skills of autonomy (Chappell, 1992), shifting an ideology of liberation to one of oppression (Simpson, 2018). The government white paper 'Valuing People' (DoH, 2001), was produced in response to ongoing reports of poorly planned and co-ordinated services for PWID, followed by 'Valuing People Now' (DoH, 2010), which emphasised greater personalisation for PWID.



'Person-centred care' is currently recommended as best-practice for organisations providing residential-care for PWID who exhibit challenging behaviour (NICE, 2015). This approach prioritises individual's preferences, needs, and goals, involves the person in decisions about their care, respects autonomy, and considers their unique values, beliefs, and circumstances. The aim is to ensure that care is tailored to each person's specific requirements, promoting dignity and empowerment (Barr et al., 2020). However, Barr et al. (2020), describes that provision of person-centred care for PWID has not been implemented effectively and consistently across services, recommending two areas for improvement; developing staff's skills, competence and confidence in communicating with PWID and promoting authentic, empathetic engagement which emphasises shared decision making.

#### 1.4.2. Children's Residential Care in Policy

1.4.2.1. Children's Social Care Reform, 'Stable Homes Built on Love': In 2022 an independent review of Children's Social Care in England described a fragmented system under extreme stress, a profit driven, crisis focussed culture with inadequate placement provision which damages children's chances at maintaining stable relationships, inconsistent mental health provision and lack of family support (MacAlister, 2022). In response the government published a strategy, 'Stable Homes, Built on Love' (DfE, 2023) setting out to reform children's social care and decrease mental and physical health disparities faced by care-experienced children. Amongst its commitments, the strategy highlights plans to enhance professionals understanding and skills to enable them to respond to the mental health needs of care-experienced children, acknowledging that for this strategy to be effective they need to do more for disabled children. Criticisms of this strategy include lack of detail on how it will be achieved in practice and reliance on existing NHS mental health systems, rather than tailored support (Rainer & Abdinasir, 2023).

1.4.2.2. Safeguarding of Disabled Children: In 2021, serious and multiple abuses were uncovered in three residential services for YPWID in the UK, prompting a two-phase national review (CDC, 2022). Phase 1 sought to understand factors which had contributed to the malpractice, highlighting multi-systemic failings, arising from inadequacy in leadership, poor training, minimal

staff support and regulatory failure. The review highlighted that trauma was often unrecognised from the outset of placement, with ID being the focus for intervention and detailed a lack of early, integrated multi-agency support (eg. mental health support). Phase 2 (CDC, 2023) outlined nine national recommendations for improvement, including; improving quality of leadership and safeguarding culture, development of workforce skills in relation to communication and behaviour, development of advocacy frameworks for YPWID and complex needs, improved engagement of families and ensuring appropriate and sensitive support for children from racialised backgrounds. The report called for urgent investment in wages, recruitment, training and staff support, describing that the workforce is undervalued in relation to the complexity of the role, particularly considering the high levels of profit which larger residential services generate. The government published a response committing to reform community support, commission residential services closer to their family home and focus on workforce development and stabilisation (DoE, 2023a).

One aspect of the governmental response was to launch a census, gathering information on the children's residential care workforce. Findings demonstrated the majority of homes reported issues with recruitment and retention, with many staff leaving residential childcare because of the pressures involved, burnout or for better working conditions elsewhere (DfE, 2024). Staff recruitment and retention have been longstanding issues in residential childcare facilities, with research describing key contributors including perception of young people's difficulties, heavy workload, poor pay and poor organisational support (Colton & Roberts, 2007).

#### 1.4.3. Residential Support Workers

The term 'RSW' refers to staff in community residential homes, who support in activities of daily living, although other terms exist for this role across the literature. RSW form a key part of the social-ecological system of YPWID in residential services, and the quality of their work significantly impacts the quality of life of those they support (Hastings, 2010). Described as 'the forgotten frontline', the children's residential care workforce has been under-researched, despite the physically and emotionally demanding nature of the role, and lacks

the supportive mechanisms associated with professionally registered roles (Parry et al., 2022).

Compared to other health and social care professionals, RSW represent a socially disadvantaged group. A recent census of the child residential care and residential school workforce (non-ID specific) highlighted that staff are predominantly female, aged under 44 years with a third aged 25-34 years, with those in non-supervisory roles paid little over minimum wage. A similar workforce profile has been reported in adult ID services, though high percentages of RSW from racialised groups in urban areas are also reported (Skills for Care, 2018). RSW working in ID and children's services also report an increased incidence of ACE's compared to the general population (Keesler, 2018, Esaki & Larkin, 2018).

1.4.3.1. RSW experience in the literature: A body of literature exploring RSW experiences across child and ID services, reports high levels of work-related distress, which has been conceptualised as moral injury, burnout and vicarious trauma.

'Moral injury' refers to personal conflict faced when an individual's moral and ethical values are at odds with what is required of them by those in power, this 'morally challenging' event can in turn cause psychological distress (Jameton, 1977; Morley et al., 2019). Moral Injury has been frequently reported by RSW in children's services, related to use of restraint, poor outcomes faced by children in their care and fear around challenges they face in their role (Brend, 2020).

Burnout refers to a state of emotional exhaustion, detachment and frustration resulting from repeated exposure to emotionally challenging situations (Maslach & Jackson, 1981). High levels of burnout have been found amongst RSW in children's services (Audin et al., 2018), and Ryan et al (2021) reported burnout as a key theme for those working in ID services, commonly associated with exposure to challenging behaviour. Self-efficacy was found to moderate the effects of burnout, whilst attribution of challenging behaviour as internal, stable, and controllable was related to higher levels of negative emotion. Burnout was also linked to RSWs feelings of being undervalued by colleagues and their

organisation, alongside excessive demands, lack of control, and inadequate organisational support.

Vicarious trauma, describes the manifestation of symptoms of traumatic stress resulting from indirect exposure to others traumatic experiences (Figley & Ludick, 2017). In children's services RSW are routinely exposed to the details and affects of trauma on those they support and may witness re-traumatisation within services. A small number of studies have described elevated rates of vicarious trauma amongst RSW in child services (Audin et al., 2018; Borjanić Bolić, 2019), and in ID residential schools (King et al., 2022), with increased rates as compared to RSW in adult services, attributed to time passing since trauma occurred (Boamah & Barbee (2022). Baker et al. (2019), reported high levels of vicarious trauma amongst staff supporting children and adults with ID, describing perceived organisational support as a mediating factor.

Many RSW also report positive experiences of their role, in ID services this has been associated with witnessing clients develop new skills and feeling appreciated (Ryan et al., 2021), whilst those in child organisations have described pleasure in helping others, associated with pride and commitment to their role (Audin et al., 2018).

## **1.5. Scoping Review**

A literature review explored the following questions:

- What is the range of research on the understanding of trauma amongst staff supporting YPWID?
- What is staff experience of supporting YPWID who have experienced trauma?

The aim of the review was to explore characteristics and concepts identified in the literature and investigate gaps in knowledge. A scoping review was considered an appropriate method and a systematic approach was employed, as defined by Peters et al., (2020). The following databases were searched: PsychInfo, SCOPUS, Science Direct and Cinahl, together with literature on open-source platforms such as Google Scholar and ResearchGate. Subject

indexes were used for individual databases, where possible, to maximise results. Inclusion criteria are detailed below.

Inclusion criteria:

- Primary research published in peer reviewed journals in English language
- Qualitative, quantitative and mixed methods research
- Relevant to at least 3 subject terms (Appendix A)
- Research pertaining to the experience and knowledge of staff working with YPWID in residential care settings.
- Research pertaining to individuals with ID ranging from mild to profound
- Due to minimal results, overlap in age between child and adult residential services and lack of data on ID diagnosis in child residential services, research pertaining to staff working in ID residential care with adults (18+) and staff working with young people in residential care with no ID specified was also included.

Search terms, exclusion criteria and final search strategies are listed in Appendix A.

Initial searches in July 2023 incorporated all subjects, revealing no relevant results. Further searches were completed between August-September 2023, refining the search strategy by systematically inputting combinations of three subjects on each data base (see Appendix A), filtering based on the other subjects to refine results where possible. Reference lists of relevant studies were visited to identify further research.

As no research incorporated all subjects, three specific avenues were explored in detail:

1. To explore the range of knowledge and experiences of RSW supporting people with ID who have experienced trauma, where age was not specified or in adult services
2. To explore the knowledge and experiences of RSW in child services where ID is not specified

3. To explore perspectives on trauma of other members of the professional network supporting adults and children with ID

The review results are presented in Figure 1.

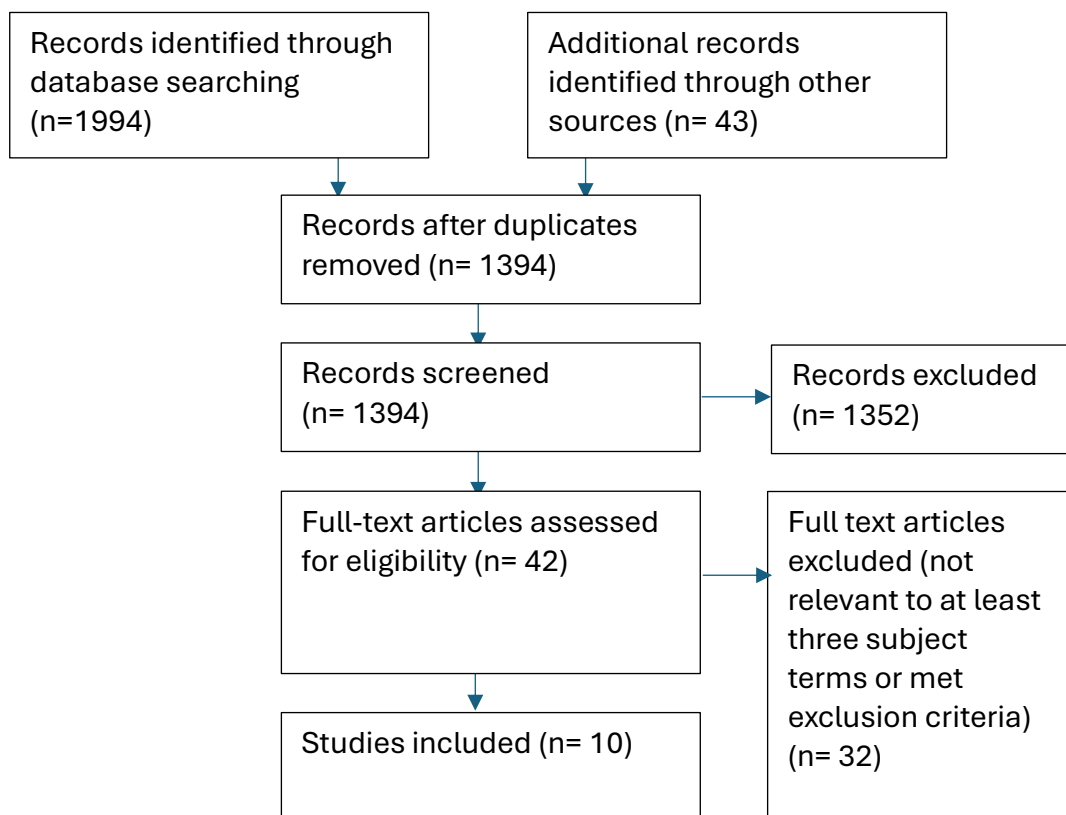


Figure 1. Scoping review results

The review sought to extract the following data from included articles; study aims; participants; methodological approach; themes or outcomes; main findings and implications. This information is outlined below.

#### 1.5.1. Research in Adult ID Residential Services Exploring Staff Perspectives on the Impact of Trauma.

McNally et al. (2022), interviewed RSWs, managers and specialist practitioners in adult ID services in Northern Ireland, using a framework based on SAMHSA (2014) TIC for analysis. Findings indicated that staff were aware of trauma-related vulnerabilities in PWID, and recognised that trauma could impact behaviour, but lacked understanding of its impact on physical health. Participants emphasised the value of safe relationships, but demonstrated least knowledge in the area of 'resisting-retraumatisation'. There was consensus on the need for training, though change at the organisational and individual level

was not addressed. Barriers to TIC included resource constraints, staffing issues, and conflicting priorities. This is the first known study exploring residential staff's understanding of trauma in the ID population, highlighting existing knowledge and areas for training. Framework analysis quantified the knowledge base of participants, which may be appealing to services considering TIC implementation, however it did not allow for deeper exploration of latent or experiential factors which could reveal further areas for consideration. This study and a subsequent project involving PWID (McNally et al., 2023) was used to co-produce a TIC framework for adult ID services (McNally, 2022).

Gray & Abendroth. (2016), examined perspectives of 60 support workers in UK residential and day services, in supporting PWID who had experienced loss (bereavement and relationship loss). Thematic analysis highlighted participants awareness of both heightened and reduced emotional and behavioural expressions in response to loss. Participants described the impact of loss may be particularly challenging for PWID as their cognitive impairments may make them vulnerable to cycles of protracted, traumatic grief and re-experiencing, also highlighting the role of support workers in supporting the grief process. Analysis was driven by focus on grief processing, so may have missed broader themes relevant to trauma. Although one interview question addressed challenges in supporting loss, no systemic, organisational or personal challenges or barriers were identified. Furthermore, participants were encouraged to discuss cases of recent loss, meaning the potential impact of loss during childhood, or those unknown to staff, were not considered.

#### 1.5.2. Research in Child Residential Services Exploring Staff Experiences and Perspectives on Supporting With Mental Health and Trauma Related Needs.

Furnivall et al. (2007), explored how RSW in Scottish children's homes understood the mental health needs of those they support. Questionnaires designed to elicit qualitative and quantitative responses were distributed to a range of staff, 104 RSW responses were analysed and described in comparison with other professionals. RSW demonstrated awareness of complex needs, though they acknowledged links with trauma less than professionals, discussed

as potentially reflecting the normalisation of these experiences. Findings highlighted the multi-systemic challenges RSW face in caring for young people with complex needs in residential care. RSW faced greatest levels of exposure to residents challenging emotions and behaviours, and experience heightened levels of emotional distress in relation to their role, compared to other staff. It was suggested that RSW hold particular skills in relationship building, which can support positive therapeutic outcomes if professionals work collaboratively with RSW. This study adds to the literature by emphasising the relational skills of RSW alongside evidencing their specific support needs, however it did not specifically focus on trauma or the impact of ID, although these were discussed as common issues. The methods of qualitative analysis were unclear and may have focussed on data content over latent meaning.

McElvaney & Tatlow-Golden (2016), interviewed 26 staff, including RSW, across Irish social care and youth justice systems, including residential services, to explore perspectives on youth mental health needs. Thematic analysis highlighted staff experiences of helplessness, frustration, and powerlessness related to the complexity of children's emotional and behavioural presentations. Inadequate systemic responses and multiple barriers to inter-agency working were identified, including competing priorities, limited resources, and poor information-sharing. Proposed solutions included early psychological intervention at a child's point of entry to residential care, stabilising placements, and commitment to inter-agency collaboration through better systems of communication. The study emphasised the necessity of addressing vicarious trauma and supporting practitioners through training and skill development. This study's strength in capturing the views of participants from diverse professional backgrounds may also have limited the depth of specific profession-based perspectives, which may be crucial in understanding challenges in inter-agency collaboration.

Kor et al. (2021), interviewed 26 staff, from three organisations, investigating their experience of barriers to supporting young people in Australian residential care. Participants included RSW, managers, therapeutic specialists, caseworkers and team leaders. Framework analysis identified six barriers to implementing therapeutic residential care: Inconsistent operationalisation, crisis-



driven referrals and assessments, problematic placement configurations and client mix, inadequate workforce development, emotional burden of care, and limited clinical support. Findings highlighted RSW's insight into how barriers to care directly impact young people; Crisis-driven practices and poor inter-agency information sharing led to inadequate care plans and inappropriate placements, risking re-traumatisation of the young person due to volatile intra-group dynamics; Staff's experience of feeling undervalued and overwhelmed in demanding roles made it difficult for them to maintain emotional availability, which was linked to increased emotional and behavioural disturbances in the young people. Echoing previous research, barriers were identified at the organisational level, including resource limitations and staffing issues, and beyond this, describing inconsistent and inaccessible support from external services. The study's focus on barriers may have limited exploration of staff strengths and hopes for supporting clients.

Abraham et al. (2022), interviewed 22 RSW from five homes across England and Wales to understand their experiences supporting young people who had experienced maltreatment, with aims of gaining insight into RSW understanding of trauma and its impact. Thematic analysis indicated that RSW felt undervalued due to societal perceptions and wages which were incongruent with the demands of their role. The ability of RSW to care for young people was reduced by the roles emotional impact, multiple competing demands, and insufficient, inaccessible support from external agencies. Participants described learning from experienced colleagues and coping with work stress through mutual support. This study further demonstrated the need for systemic change to enable RSW to provide good quality care. A key limitation was that participants and researchers belonged to one organisation, which may have limited diverse perspectives, and made participants hesitant to raise service-related concerns. Staff understanding of trauma and its impact was not discussed despite the studies aims.

#### 1.5.3. Research Exploring the Insight and Experience of Other Staff Working With Adults and Young People With ID Who Have Experienced Trauma

Keesler. (2014), interviewed service co-ordinators in the US, to explore their understanding of trauma and it's impact on adults with mild ID, analysing using

a grounded theory approach. This study is an interesting addition to the literature, as service co-ordinators are likely to have privilege to historical information. Findings indicated that participants believed factors associated with ID could increase vulnerability to trauma. They also described connections between adverse experiences and behaviours, including behaviours aimed at avoiding further adversity. Participants described awareness of environmental, relational, and systemic factors which perpetuate trauma's impact and discussed ways that PWID adapt to adversity, emphasising the role of services in supporting healthy coping mechanisms. Participants often conceptualised trauma from the perspective of abuse, which may be inadequate in understanding its true prevalence and impact. The study is limited as the analysis did not reach theoretical development, additionally, issues with information-sharing abound at every level and may limit service co-ordinators perspectives. Furthermore, the research did not explore the impact of trauma on young people or those with varied levels of impairment.

Kildahl et al. (2020), interviewed mental health clinicians working with adults with ID and Autism in Norway, to explore their understanding of PTSD in this population. An interpretative phenomenological analysis highlighted clinician's perspective that limited coping resources and unavailability of treatment can lead to enduring distress and loss of function in PWID. Participants described that diagnostic overshadowing increased with ID severity, and trauma consideration could be limited by challenges interpreting behaviours and lack of historical information. Many participants admitted overlooking PTSD in PWID, emphasising the need for trauma-focused assessments. Clinicians felt RSW, who are with PWID daily, may be best placed to identify trauma related distress, whilst also implicating residential services in the cause and perpetuation of trauma. This study highlights the need for trauma education of all those in systems around PWID, and the importance of a trauma-informed approach. The design allowed for in-depth exploration of participants knowledge and meaning making, however its specific cultural context may not be relevant to the UK healthcare system.

Truesdale et al. (2019), interviewed 25 ID healthcare professionals from across the UK to understand their insight in working with PWID who had experienced

trauma, exploring their views on necessary support and potential barriers. Thematic analysis highlighted challenges faced by a variety of professional services, which aligned with previous research, including; diagnostic overshadowing, referrals which did not consider historical adversity, lack of evidence-based treatment options for PWID, ability of PWID to engage with treatment and time constraints. Participants described the importance of multi-disciplinary working and the need for services to be trauma aware and person centred to ensure assessment and treatment pathways meets client needs. Training was a key priority across services to increase awareness, alongside supervision and support. This study specifically highlighted professional perspective on the lack of training and knowledge in residential services around the impact of trauma on PWID, which was compounded by issues with staff retention. Although multi-disciplinary working was cited as a key theme supportive to effective care, there was a lack of description of how this could be achieved and any specific barriers, it may also have been relevant to explore methods and barriers for implementing training and education.

Simpson et al. (2022), interviewed social workers and other social care professionals in New Zealand to understand their experience of supporting YPWID who had experienced trauma. Thematic analysis revealed challenges in recognising the impact of abuse, emphasising the importance of engaging caregivers for behavioural interpretation. Further barriers to support included a lack of understanding of ID and ambivalence towards the needs of YPWID who have faced adversity. Participants expressed a sense of duty and advocated for systemic changes to better support YPWID, emphasising the value of long-term, trusting relationships for quality assessments and sensitive support. This study adds to the literature by exploring the specific experiences of social care professionals in supporting YPWID, highlighting the importance of addressing wider systemic influences which can cause and perpetuate trauma and for integrating TIC into social services. Limitations included a lack of exploration into the personal impact of this work, the study was also conducted within a specific cultural context, unlikely to translate directly to UK systems.

## **1.6. Rationale for Current Research**

There has been increasing focus on researching the impact of psychological trauma in PWID (Beail et al., 2021; Keesler, 2014a, 2014b; McNally et al., 2021). Trauma is a significant issue for YPWID with implications for lifetime psychological and physical health, especially for those in residential care are likely to have needs related to disruptions in attachment. Whilst a trauma-focus can be adopted within practices for behavioural and communication support in ID services, there is rationale for a systems level focus on trauma and TIC has achieved positive results amongst children's services. However, TIC implementation studies in ID residential services have highlighted multiple barriers. TIC represents a culture-shift towards prioritising the physical and relational safety of all service users and staff, necessitating systemic change and a 'bottom-up' approach which considers the values, needs of frontline staff and barriers they may face, whilst harnessing 'top-down' support (Goad, 2021; McNally et al., 2023). This has relevance for UK Policy which has emphasised the need to develop community capability in supporting PWID with complex needs and behaviours, to improve the safeguarding of YPWID, develop the child residential ID workforce and improve services for young people in residential care.

Prior to any implementation initiative, it is crucial to explore the experiences and insight of frontline staff. The scoping review identified a significant gap in the literature: No studies specifically explored RSW knowledge of the impact of trauma in YPWID and their experience of supporting these young people.

Existing studies exploring RSW and other key stakeholders' insight into the impact of trauma in residential services for children where no ID is specified and for adults with ID, highlighted that RSW demonstrate an awareness of trauma and the various ways it can impact those they support. However, they also described common systemic barriers to care in terms of poor inter-agency working, lack of time, resource, and issues with staffing, all of which significantly impact clients. The experience of RSW in child services could act as a further barrier to effective care, as RSW report the highest exposure to trauma-related behaviours, whilst receiving the least structured support, and commonly reported overwhelm, burnout and work-related stress. Other stakeholders

displayed additional insight, describing various trauma-related behaviours, barriers which prevent consideration of trauma and highlighted the crucial role of RSW, echoing concerns about inter-agency collaboration.

There is strong evidence that addressing childhood adversity can be particularly valuable in improving health and well-being outcomes (Marmot et al., 2008, 2020; WHO, 2014, 2018). Based on the literature review, it was determined that investigating the knowledge and perspectives of RSWs in child ID services could provide valuable insights into supporting this vulnerable population, with the aim of informing TIC initiatives in these services. The age range of 12-25 years captures the period when most YPWID in residential care enter the system and aligns with current health and social care legislation for service provision (Children and Families Act, 2014). Understanding RSWs' perspectives on supporting trauma in YPWID is particularly relevant to the role of Clinical Psychology, which often requires collaboration with staff and services caring for YPWID with psychological or behavioural difficulties and may involve the implementation of trauma-focused strategies.

### **1.7. Research Aims and Questions**

This research intends to explore how RSW understand and respond to trauma in YPWID, alongside barriers and facilitators to support, with the aim of understanding how to enhance the capacity of residential care services to implement trauma-informed practice for YPWID. These aims will be addressed through the following research questions:

- What do RSW understand about how traumatic/adverse experiences impact YPWID?
- How do RSW think they can best support YPWID who have experienced traumatic or adverse life events?
- How does this fit within service context?
- What is RSW's experience of supporting YPWID who have experienced trauma?
- How can RSW insight be used to assist residential services in integrating TIC practices?

## **2. METHODOLOGY**

This chapter describes the epistemological position of the research, providing rationale for the approach, followed by an exploration of researcher reflexivity. Procedures for the study are explained, including ethical issues, recruitment, sample, data collection and the process of analysis.

### **2.1. Epistemological Position**

This research adopts a critical realist stance to explore individual participants perspective on trauma in YPWID. Critical realism is a position described as combining ontological realism with epistemological relativism (Braun & Clarke, 2022). It broadly assumes the existence of a real world, whilst theorising that what can be accessed is a social production of reality, with multiple representations and perspectives gained through a lens influenced by language and culture (Braun & Clarke, 2022). This position acknowledges the researcher as subject to the same contextual influences and all interpretation as tentative and provisional (Braun & Clarke, 2022; Maxwell, 2012).

In this research, a critical realist stance acknowledges that certain experiences may be traumatic for YPWID, possibly affecting their wellbeing, behaviours and relationships. It acknowledges that RSW's understanding of YPWIDs experiences and behaviours are likely to be influenced by their cultural context, language, experiences and social constructions of ID. It is recognised that these accounts are subject to the interpretation of the researcher, and a reflexive approach was adopted throughout the research process (See section 2.4).

### **2.2. Design**

Critical disability studies scholars argue that many disability issues are not quantifiable, advocating for methodologies which allow for exploration of everyday meaning-making processes (Goodley, 2017). RSWs play a crucial role for YPWID in residential care, and the research questions are concerned with capturing their experiences and perspectives, which may significantly impact the lives of those they support. A qualitative design was employed to allow for a

deeper and nuanced understanding, acknowledging that RSW's constructions of trauma and its effects may vary from academic and professional discourse.

### **2.3. Thematic Analysis**

Thematic Analysis (TA) identifies patterns and meaning in qualitative data, illustrating key themes and clusters of meaning, involving emotional, cognitive and symbolic elements (Hoffe, 2012). TA has diverse origins (Braun & Clarke, 2022), though a common understanding is that it developed through a qualitative refinement of content analysis, retaining a systematic approach but going beyond, to address implicit themes and structures (Hoffe, 2012). TA is now a widely used 'family of methods', involving elements from various orientations, with approaches ranging from reflexive to postpositivist (Braun & Clarke, 2022).

In TA, a 'theme' refers to patterns of meaning, which can be drawn inductively from the data, or established deductively based on theory, containing both implicit and explicit reference to a subject (Hoffe, 2012). Some examples of TA focus only on surface level content, demonstrating closer alignment with quantitative paradigms (Braun & Clarke, 2022). This thesis will explore inductive and deductive themes, aiming to interpret meanings beyond descriptive accounts.

### **2.4. Reflexivity**

Within a qualitative paradigm subjectivity is considered inherent, as researchers bring with them layers of personal context, experience and values (Harper & Thompson, 2012). Rather than aiming for 'unbiased' knowledge generation, TA suggests researcher subjectivity as a valuable tool when consciously and reflexively incorporated into design and analysis (Braun & Clarke, 2022; Gough & Madill, 2012). Reflexivity refers to a critical attention to, and reflection on research practices and the researchers role in knowledge production (Harper & Thompson, 2012). Distinctions have been made between styles of reflexivity, including; functional (examining how research methods, shape research); disciplinary (how discipline affects knowledge production), and personal (how researchers personal values, assumptions and social locations shape their work) (Braun & Clarke, 2022; Harper & Thompson, 2012). Additionally, scholars

emphasise the importance of addressing the politics and power dynamics in the research process (Braun & Clarke, 2022).

#### 2.4.1. Reflexive Position

2.4.1.1. Personal: My social location was considered; I am a white, cis-gender, non-disabled, female. I have occupied a paid care role, though not in an ID context. My sister joined my family via foster care and has a diagnosis of ID. She moved to residential care in adolescence, and I have advocated for her within various homes. This experience influenced my interest in, and position on this research and my initial interest came from witnessing a lack of trauma-informed care in residential care services, thus my starting position on this topic was informed by this personal perspective. Over time I have had varied experiences with services and staff and have come to understand how crucial RSW's perspective is. I have also worked with RSWs and services professionally during a community ID trainee placement, developing insight into service-level challenges in implementing new ways of working. These experiences have also shaped my interest into the societal power processes and ideologies which impact the support opportunities available to YPWID who have experienced trauma.

2.4.1.2. Functional and Disciplinary: Although my values align with qualitative paradigms, my career and studies have mostly involved research with positivist orientations, and I have never conducted a study based on qualitative values, bearing risk for an unconscious drift towards positivism (Braun & Clarke, 2022). Throughout the research process attempts were made to remain aligned with qualitative values, which are intrinsically linked with this study's aims, through conscious attention to language, focus and ideas.

I have come to understand the potential impact of adverse and traumatic childhood experiences through my psychology training. The principles of TIC fit with my professional values and have shaped the research design and interview schedule. I acknowledge psychology research is mostly situated within western populations and so this understanding of wellbeing and distress will not always translate across cultures.



I acknowledge that my personal and professional experiences are likely to influence this research, I have sought to maintain awareness by adopting a reflexive stance, including keeping a reflective diary (Appendix B), and through collaboration with the research supervisor. The impact of personal and professional locations will be considered further in the discussion. However, I understand that reflexivity does not eliminate bias.

## **2.5. Recruitment**

### **2.5.1. Inclusion Criteria**

Participants were all RSW employed currently, or within the last 2 months, in UK based organisations providing residential care to YPWID (age 12-25). Time in the role was not an inclusion criterion as retention issues are common. As in previous studies (e.g. McNally et al. 2021), RSW currently working at senior and management level were included, but only if they had significant RSW experience.

### **2.5.2. Procedure**

**2.5.2.1. Preparation:** Prior to recruitment several organisations were approached to assess their interest in supporting the study. Two agreed to circulate recruitment information amongst their staff teams.

An advert was created comprising basic details of the study including length of interview and researcher details (Appendix C). The advert gave potential participants the choice to sign-up via email, or via link to a Qualtrics survey containing the information sheet (Appendix D), and consent form (Appendix E).

**2.5.2.2. Recruitment process:** Early in recruitment the advert and link were emailed to participating organisations, and others identified through online research. The advert was shared on social media platforms and groups for RSW and distributed throughout the researchers personal and professional network. After the link received over 800 false sign-ups it was removed and sign-up was possible via email only. After signing up, participants were emailed to agree a time and date for an interview and a Microsoft Teams invite was sent to their email address.

## 2.6. Participants

### 2.6.1. Sampling

The issue of sample size in qualitative research is debated. Guest et al. (2006), suggest approximately 12 interviews are required for data saturation, though Braun & Clarke (2021), argue the concept of saturation is misaligned with qualitative approaches, instead advocating for review of data depth and relevance to guide sampling (Braun & Clarke, 2022). Whilst Onwuegbuzie & Leech (2005), warn that complex engagement may be unmanageable if a data set is too large. Considering these positions, I aimed to recruit a minimum of eight participants, continuously reviewing the richness and depth of the data once the lower limit was achieved and continuing to a maximum of 15. The final number of participants was 10.

### 2.6.2. Participant Information

Ten RSWs from nine organisations volunteered their participation. Two were recruited through their organisation and the rest were recruited through social media. Participants were two males and eight females. Only two had completed specific training in TIC. Of those who had been in the role less than 5 years, two held psychology undergraduate degrees and one was in the process of finishing a master's in psychology. Their information is included in Table 1.

*Table 1. Participant demographics*

<b>Participant number</b>	<b>Service type</b>	<b>Role</b>	<b>Years in service</b>	<b>Training in TIC?</b>
<b>1</b>	Charity	RSW	4	No
<b>2</b>	Private	RSW	2	No
<b>3</b>	Private	RSW, Manager	14	No
<b>4</b>	Private	RSW	2	No

<b>5</b>	Private	Senior RSW	15	Yes
<b>6</b>	Private	Senior RSW	14	No
<b>7</b>	Private	RSW	3.5	No
<b>8</b>	Charity	RSW	1.8 (left post 6 weeks ago)	No
<b>9</b>	Private	RSW	7	No
<b>10</b>	Private	RSW, Manager	14	Yes

## **2.7. Ethical Issues**

As outlined in the BPS (2021) Code of Ethics, potential ethical issues were considered.

### **2.7.1. Ethical Approval**

Ethical approval was granted by the University of East London's Research Ethics Committee (Appendix G).

### **2.7.2. Informed Consent**

Potential participants were provided an information sheet (Appendix D) detailing the background the research background and aims, what participation involved, right to withdraw, potential disadvantages to participation, confidentiality, dissemination, data management. ethical approval and the researchers email address for questions. Participants were then required to respond to 11 statements and sign the consent form (Appendix E), confirming informed consent. At interview stage participants were asked if they had any questions regarding the information sheet, were reminded of their right to withdraw and were asked to provide verbal consent.

### 2.7.3. Confidentiality

Data was collected and stored securely, according to methods detailed in the approved Data Management Plan (Appendix H). During transcription all identifying information was removed. Data was saved alongside a participant number so it could be identified if necessary (e.g. if the participant requests to withdraw). Personal data was not stored longer than necessary, recordings were deleted following transcription.

### 2.7.4. Further Ethical Considerations

It was recognised that discussion of trauma may cause distress and questions may lead participants to reflect on work experiences linked to vicarious trauma. A debrief form was provided at the end of the study via email (Appendix I), this included signposting to mental health and wellbeing support services. Participants were also offered a 30min debrief call in the 2 weeks following the interview, though none requested this.

## **2.8. Data Collection**

### 2.8.1. Interview Schedule

The interview schedule was constructed prior to recruitment and was designed to fit closely with the research aims. Inspired by a study with similar aims (McNally et al. 2022), questions mapped on to SAMHSA's (2014), assumptions of trauma informed care, with questions broadly based on the topics of 'realising trauma', 'recognising trauma', 'responding to trauma' and 'resisting traumatisation'. A further question required participants to comment on a quote defining childhood trauma, encouraging explicit reflection on the subject of trauma and its relevance to their role.

To aid consideration of the accessibility and relevance of the interview schedule two pilot interviews were conducted. This data was not included in the analysis, though all other procedures remained the same. Details of the pilot interview participants are described in Table 2. Recommendations included slight changes to wording, making questions more succinct and suggestions of prompts to encourage participants to access their experiences, as well as writing questions in the Microsoft Teams chat.

Through consultation with the pilot interviewees, it was decided that the term 'difficult life experiences' should be used instead of trauma, in acknowledgement of the fact that participants might relate the term 'trauma' to specific cases abuse or singular traumatic events and neglect to consider other challenging experiences (e.g. moving to residential care) which may be experienced as traumatic.

The interview was semi-structured and flexible, during the interview participants were asked further questions to enable them to expand on their points.

*Table 2 Pilot interview details*

<b>Role</b>	<b>Organisation</b>	<b>Reasons selected</b>	<b>Consulted on</b>
Assistant Psychologist	Community ID psychology	Basic psychological knowledge of trauma. Work with ID residential organisations.	Language accessibility Appropriateness of questions
Senior RSW	Adult ID residential, previously child ID residential	Long term experience working with PWID across the lifespan.	Language accessibility Appropriateness of questions Relevance to context

### 2.8.2. Interview Process

Interviews took place on Microsoft Teams for a duration of 45-80minutes. Participants were not required to have their camera on, though the researchers camera remained on. Questions were read and then provided in writing in the Microsoft Teams chat to increase accessibility. At the start of the interview

participants were asked to confirm basic demographic information. Effort was made to put participants at ease through informal conversation.

Participants were asked each of the questions in the interview schedule (Appendix J), though prompts depended on their answers. Follow up questions were asked when a topic seemed important to the participant, or if they did not expand on an answer automatically.

## **2.9. Data Analysis**

### **2.9.1. Transcription**

Transcription refers to the process of preparing audio data for analysis. During this process the researcher chooses what is transcribed and the style of transcription used, and thus transcription is a theoretically informed activity (Ochs, 1979). There are various styles of transcription, suiting different methods of analysis. Orthographic transcription provides a thorough record of what is spoken with little focus on non-semantic sounds, and is described as detailed enough for most TA (Braun & Clarke, 2013).

In this study interviews were automatically transcribed and recorded on Microsoft Teams, the researcher listened to recordings and edited transcripts using an Orthographic approach. Notation was made for emphasis (*italics*), contextual information [square brackets], pauses (...) and overlapping speech (-).

### **2.9.2. Reflexive Thematic Analysis Process**

The analysis was based on the six phases of reflexive TA set out by Braun and Clarke (2022), detailed below:

1. Data familiarisation: Interviews were listened to whilst transcripts were edited. Transcripts were reviewed multiple times whilst recording initial analytic thoughts.
2. Coding: All interviews were uploaded to qualitative data analysis software (NVivo). The entire dataset was systematically labelled with analytically meaningful codes. Initial coding was exploratory and fine grained with attention to semantic content. Coding evolved through re-coding with

broader codes, attending to latent content and relevance to the research questions. (Appendix K provides a sample of coded transcript).

3. Generating candidate themes: Codes were printed and the following stages took place on paper, though data extracts were referenced throughout. Clusters of codes were compiled to form candidate themes, based on commonality in ideas and concepts, shared patterns of meaning and how they addressed the research questions. When candidate themes were thought to address the research aims and offer a thorough representation of the data, all relevant data was organised within these themes (Appendix L provides pictures from the theme generation process).
4. Developing and reviewing themes: Candidate themes were evaluated against coded extracts and the full dataset to judge their representation of shared and meaningful patterns. Themes were examined together to ascertain if they demonstrated patterns relevant to the research questions and existing literature. During this process some themes were discarded, revised, or grouped, aided by thematic mapping (See Appendix M).
5. Defining and naming themes: A brief description of each theme was written to assess its ability to describe the data, if further development was required, phase four was repeated. Themes were named according to core characteristics.
6. Writing: Writing commenced in phase 3, evolving alongside theme development. Familiarisation notes, data extracts and analysis were integrated in a way which aimed to describe the data, answer the research questions, and contextualise within existing literature.

2.9.2.1. *Quality Assurance*: To aid quality assurance the research supervisor was consulted at each stage of the analysis process. They reviewed coding and themes and made suggestions to guide the process and aid reflexivity.

### **3. RESULTS**

#### **3.1. Chapter Overview**

This chapter presents the results of the analysis, described in the Methodology section, here the themes are defined and explored in detail, whilst theoretical interpretation will be provided in the Discussion.

### 3.2. Final Themes and Subthemes

Analysis produced three final themes and nine subthemes. These are presented in Table 3.

Anonymised extracts will be used to illustrate themes, minor edits have been made in places to make quotes concise and aid reader focus. When words or phrases are omitted, they are replaced with (...)

*Table 3. Final Themes and Subthemes*

<b>Theme</b>	<b>Subtheme</b>
<b>Trauma in the System</b>	Invisible in the Community
	Abandoned by Services
	Organisational Stress
<b>Recognising, Responding and Resistance to Trauma</b>	What Has Happened to You?
	Recognising the Impact of Trauma
	Responding: Creating Safety
	Responding: Moving Forward and Resisting Traumatization
<b>More Than a Job</b>	Personal Responsibility and Impact
	Valuing Residential Support Workers

In summary, participants described a working context which embodied adversity at various levels, impeding their ability to provide the support they believe their clients need. Participants described ways they attempted to resist the barriers imposed by the system and aimed to make reparations within their clients lives through the support they provided. They discussed their relationship to their role and its personal impact, alongside a sense of duty and intrinsic personal motivation to support YPWID in residential care ('residents'), acknowledging the



complexity of their role and the value which should be placed on it by their organisation, external services and society.

### 3.2.1. Theme 1. Trauma in the system

A consistent theme was participants experience of operating within a system which caused and perpetuated harm on various levels and posed barriers to care, describing challenges within communities, external services, and their organisations.

3.2.1.1. Subtheme 1. Invisible in the community: Participants described how the YPWID they supported are isolated by societal factors such as stigma and lack of community resource.

Participants noted negative societal attitudes towards PWID

*P10: You have members of the public (...) they look at them as if to say, "God, why do you bring them out in public?" And if they think that service users don't realise that, they absolutely do.*

Participants discussed the limited opportunities for community participation available for residents, either due to lack of consideration of their needs, funding cuts, or financial inaccessibility.

*P4: Because of the cuts they have got rid of loads of classes and teachers, reduced classes (...) so my boys have not been able to get on any (...) it's had a really big effect on them.*

*P7: I think there's hardly any activities for kids with autism and learning disabilities (...) I was looking at one place, it was like...one of them trampoline places or something? And it was like...an hour...one Sunday a month or something? And I was like, oh that's a bit....rubbish.*

*P8: I know that was not good for them because they kept asking on doing things, but they couldn't because of the budget and the finance issue.*

Participants described how lack of access to community activities might impact residents, identifying boredom, having too much time to dwell on traumatic events and impact on their relationships.

*P7: ...we do have quite a few incidents and...yeah (...) it's possibly a lot of...boredom.*

*P4: ...all you can do is think about what has happened, not what you're gonna do. 'cause...there's nothing to do, you know.*

*P1: If they had a community (...) more people around them, I don't think that co-dependency [with another client] would have been there.*

3.2.1.2. Summary: Participants described challenges associated with wider societal views related to YPWID and how this pushed them into positions of isolation, the lack of opportunities posed challenges for staff when supporting YPWID with complex needs.

3.2.1.3. Subtheme 2. Abandoned by services: Participants described experiences of feeling voiceless and abandoned when working with external services, with particular focus on social services and mental health services, detailing the impact this had on residents.

It was implied that external professionals often do not value RSW input, despite their proximity and experience working with the residents.

*P3: I think, as support workers, we're always bottom of the food chain. We're the ones who get listened to the least...but have the most contact with the individuals.*

Participants felt unsupported by services and under-skilled in supporting residents who had needs beyond which they were trained to support, whilst residents remained on long waiting lists for qualified support.

*P5: I get concerned about the young people (...), we need some more types of...support out there to help us (...) CAMHS are...like overwhelmed (...) So we need some more people out there to support...and...trying to understand (...). They need more professionals involved, outside professionals.*

When services were engaged, participants felt the support sometimes did not meet the needs of the residents, that professionals did not take time to get to know the client and were more interested in procedures.

*P4: ...Me standing there saying breathe for three seconds and hold it and then out your nose and then your mouth (...) at that point, it doesn't work, you know (...) like there's about 10 other steps that we have to take before we get to that point, which you know, doesn't really get recognised.*

*P9: ...increase their visits when they first meet a patient, because then that will help you understand what's going on (...) but sometimes they come once in a month or once every two weeks (...) some of them they feel like if they put their inputs like into their care plans it helps.*

One noted how mental health services can be quick to give up on YPWID, perpetuating feelings of abandonment.

*P9: most of them as well they have this habit of saying "ohh I've said it once. He said no, she said no, I'm not going back to it. If they wanted, they can always come back", but some of them [YPWID] want that patience. They feel like someone care and when you show the attitude they see like, "OK, you don't care. So what's the point of me telling you anything or participating in anything?"*

Participants described mistrust of external services. They described a lack of faith in the system and feelings of hopelessness.

*P10: When these people are supposed to be the ones who are in charge of, putting you somewhere to protect you (...) you just think, if your own social worker who should know your background has put you somewhere that has questionable integrity (...) and then only move them because the home is being shut down by CQC (...) it's incredibly sad.*

It was recognised that shortcomings of social services and mental health services were due to staffing issues.

*P10: ...they [social services] are so, so impacted by the amount of people in the system to the ratio of how many social workers they actually have. So it's not even just the fact that, OK, they haven't got a named social worker. There's nobody invested. You, get social workers that come in and they don't even know the person that they're talking about.*

*P7: like we all know mental health services aren't the best. Umm...but again I think that's...down to staffing again, it's just the NHS in general, isn't it?*

Participants described feeling they must convince or 'fight' to activate adequate support from external services.

*P3: You have to fight social services (...) you have to then go back to the medical field and fight them for something.*

Whilst one noted the value of professionals who are consistent and who listen.

*P9: [professional's name] was very helpful. Yeah, because she was with this young person for a while, so she knows her before even she moved into her place. And she was also there, she was willing to listen. She was amazing.*

Inter-agency information sharing was a key issue, participants felt they did not receive adequate information on resident's histories.

*P8: I would speak to their social workers about these things [historical events] that I have discussed with residents and they would not know themselves. So it was really hard. I don't know how to approach that situation.*

*P10: I've gone back to social services and I've said to them, can you please send me a full itinerary of this person's life? And they have come back to say "we haven't got that". It's like, well, hold on a minute. This person became a LAC [looked after child] (...) when they were very young and now they're in early adulthood, how can you not have that information? And they just say, "We don't".*

They described how this makes it difficult to provide care which meets the needs of the residents.

*P1: How can we support...our client to work through the feelings if we don't know what's gone on?*

*P6: The trauma is not put down on a piece of paper or certain events are written, but the triggers are not there. What triggered it, why they're being like this (...) we wasn't given that information.*

One described their experience of both social services and health services omitting or discarding important information.

*P10: The common thing that I have seen as a care worker is that they don't give you all the information in [when coming out of] hospital because if they do, you're less likely to take them.*

*P10: If I'm really honest with you, a lot of it has been discarded because there's something behind it. Usually because they have suffered from some sort of abuse (...) within the homes that they have previously been in...and they've hidden that.*

3.2.1.4. *Summary:* Participants described feeling that both RSW and YPWID were unsupported by external services, leading to mistrust in the system and creating challenges in providing care which is tailored to the young person's needs.

3.2.1.5. *Subtheme 3. Organisational stress:* Participants discussed mixed experiences of organisational life, a minority felt generally satisfied with their organisation, however many described organisation level challenges which generated stress within their role.

A key challenge was working within the context of staff shortages, this was discussed as a self-perpetuating issue as staffing pressures led to increased workload and working environments where RSW wellbeing was not considered.

*P7: We had unsafe numbers (...) they just never got anyone else for us. They told us that they were getting someone else and they never. And one of the kids had broken one of the staff's fingers...and they questioned her going home (...) and said like "can't you stay in work?"*

*P5: So we were supposed to be doing like 2 on 3 off [shifts] and ended up doing one on one off (...) We're supposed to do 15-hour shifts, which ended up turning into 24 hour shifts (...), over working the staff, it's too much that they ask for the staff which has affected the teams and we've lost loads of staff over it.*

Experienced RSW were described as assets in supporting teams.

*P4: There are very knowledgeable people here in this team, they've been in it for like the length of my life, so it's quite it's good.*

However, increased pressures and poor working environments were named as instrumental in experienced staff leaving their roles.

*P5: I was there for a year and we lost about 80% of the staff. Original staff.*

*P10: The general consensus is that a lot of people who have worked in care for a really long time are leaving because it is too much.*

Organisations are then likely to hire inexperienced RSW, but do not provide adequate support or training, meaning junior RSW are unable to cope with the demands of the role and leave quickly.

*P1: I guess, because we're so short of staffed (...) they're kind of willing to employ anyone and it's, you know, anyone and anything and you don't need any training, you don't need any background. I don't even think you need an enjoyment in interacting with people at this point*

*P10: Obviously they're taking on non-experienced staff and I get it (...) but they're not giving them the tools or the information they need to do this job.*

*P4: I think people (...) do get quite overwhelmed and don't really understand that...what the job actually is, until they're in there (...), they don't realise the intricacies of it all and how much you kind of have to do (...) and then they just think, no, not for me.*

They described how staff shortages meant they must focus on day-to-day tasks and struggled to find time to give adequate care, attention and access to experiences for YPWID.

*P1: It sounds awful, but there's not that much time for the emotional aspects of it.*

*P7: The kids have got like, what I think is really bad, not really bad, but a bad quality of life. They just don't go out anywhere, basically because we've never got the staff to do it.*

Participants described feeling unsupported and undervalued by their organisation, describing poor pay, lack of support and resource

*P5: Most homes are focused on funding (...) It's just money to them. And another home to deal with, and yeah, put aside and don't bother being interested in it. It's, it's hard.*

*P7: Like where I am now they can't even pretend they value you (laughing)*

*P6: I don't think we get paid enough to be fair, for what we do.*

*Interviewer: What would make you feel valued?*

*P7: Just the basics (...) having gloves that fit and the correct number of staff on shift.*

Describing how lack of resource prevented their ability to complete their role

*P2: The organisation [should] provide means of transportation, it should not be like we're going out there for another means of transportation that will now be very difficult for me to take care of the children.*

Participants felt their organisation did not share adequate information about residents, one noted this could be a tactic on behalf of management to prevent RSW leaving.

*P8: The care plans were not really good, the way they were written (...). And they were very old, not very relevant.*

*P10: So as a support worker you get told...what management want you to know (...) So when we didn't get all the information, we tend to find that that is for a reason (laughing) and that is to stop panic.*

Additionally, participants discussed how the service would not equip them to recognise and support with the complex psychological challenges their clients face.



*P1: Training is the biggest one (...) I don't even think some staff know what mental health is to be perfectly honest.*

*P5: Yeah, See the trauma-informed (...) it's not the best training (...) they should get involved more therapeutic workers....But we only get trained online or through a three day course (...) But it takes years to understand it.*

*P5: They're [team] 100% not qualified to deal with it. That's how I feel like, to be honest*

*P2: I think, we should be able to analyse their trauma (...) by giving we more training.*

Whilst receiving training opportunities was related to feeling supported within their role.

*P9: In terms of training my company do provide trainings for us (...) I think overall they've been helpful.*

3.2.1.6. Summary: Whilst there were varied experiences of organisational life, many participants discussed organisational stress, which they related to the effects of poor staffing. They described how these pressures meant organisations did not prioritise the wellbeing of staff, or provide adequate support and training in working with complex clients, perpetuating staffing issues. Poor pay and lack of support and resources lead to participants feeling undervalued in their roles and impeded their ability to provide support.

### 3.2.2. Theme 2. Recognising, Responding and Resistance to trauma:

Within the context of the system in which RSW operate, attempts at compassionate, person-centred, and trauma-informed care, could be viewed as a form of resistance. RSW discussed their attempts to provide care they believed the residents needed, despite systemic challenges, and highlighted ways they would support further if they were able.

3.2.2.6. Subtheme 1. What has happened to you? Participants discussed awareness that many of those they supported had experienced adversity or trauma, and so, in the absence of being provided with good quality historical records, described the importance of building a picture of resident's backgrounds, discussing how this could aid behavioural interpretation and help tailor support.

*P10: It's very, very important to get as much information as humanly possible (...) if we have somebody who we didn't have a lot of information for, it's extremely difficult (...). It's so important because a lot of (...) people with learning disabilities that we have cared for have had quite a tumultuous background.*

*P1: I think it just helps you see a context and a background, for example for challenging behaviours or for emotional needs (...) You don't put that behaviour on the person (...). You actually think? Ohh, hold a second, it's cause of all these things before, so it helps you externalise almost.*

*P3: Knowing...a bit of his [YPWIDs] history and knowing that what his motive was like "you guys are not gonna hurt me like I've been hurt by everybody else. And I'm gonna scare you out of the place."*

Conversely, a lack of understanding of context and history affected RSWs perception and subsequent treatment of the young people.

*P1: I've noticed the staff who don't take into account, actually this might be because he's witnessed abuse in his life (...) they get a lot more frustrated and they don't have that patience*

In the absence of adequate historical information, participants discussed a variety of methods which they routinely employed to make sense of what had happened to their clients, forming a key part of the support process. This included attempting to gain more information through external agencies, and gathering information from the young people through adapting communication and behavioural observation.

*P5: We try and do what they call a life story (...) by other [any] means necessary... If we don't have that information, we do a lot of research and speak to social services, try and back date it through them.*

*P9: Most times is observation to see a frequent pattern, and then you start observing and noticing things that are triggering.*

*P9: I found it useful to use pictures and in that instance, I was able to get through to her [young person] and I got a lot information*

*P2: ...you will listen, to give them time (...) the way they talk give us idea on what is really happening in their life.*

Making sense of a resident's history required experience, time and the development of trust (Discussed further in 3.3.2.3).

*P6: When they see that people are being consistent that's when they build the trust and that's when they're able to talk about their past and what has happened to them, that's when we're able to work with them.*

*P5: There's certain ways you can pick up on the young people, but it's a lot of experience or a lot of...training is involved to understand this.*

3.2.2.7. Summary: Despite often being provided minimal training and poor-quality information, participants described the importance of understanding young people's backgrounds, using a variety of methods to make sense of what had happened to them.

3.2.2.8. Subtheme 2. Recognising the impact of trauma: Participants displayed a broad understanding of links between challenging or traumatic life events and YPWID's wellbeing, behaviours, and current needs.

Some initially struggled to describe the impact of adverse life experiences on residents. Some displayed a limited understanding of what might be considered traumatic, with focus on the effects of physical abuse.

*P6: ...they're [YPWID] not going to understand [an abuser] calling them a big fat, whatever [being verbally abusive] (...) if [an abuser] give them a smack across their face, they're obviously going to (...) feel that, they're going to understand it.*

The language of 'attention-seeking' was used by some participants. Within the context of the discussions this was received as a way of describing what was understood to be a reasonable reaction to trauma, rather than to minimise the young person's experience.

*P8: Well, it was that attention seeking (...) people would do things just to have as much attention as possible.*

*Interviewer: Why do you think they wanted to do that?*

*P8. They probably didn't get that much support from their family, so they want to feel as seen as possible.*

The impact of a range of repeated adverse experiences such as loss, neglect, moving into residential care and through multiple placements, were also acknowledged throughout the interviews. Participants also described how ID might exacerbate the impact of trauma in various ways, e.g. potentially causing difficulty understanding or making choices in their move into residential care and in processing adverse experiences.

*P7: I just can't imagine that they have an understanding of why they came and.... Yeah, all the like dynamics around it and stuff.*

*P4: It does stay with them (...) I think they hold on to things a lot more than what we actually do (...). Me, I completely forget that [adverse experiences], it's not even something that comes across in my in my day-to-day life or thinking. But with some of my young people that we look after, you can see that it still affects them, even now, 10 years later.*

Participants described that YPWID who have experienced trauma might display challenging behaviours as a way of communicating distress or when struggling to cope with emotions related to their experiences, which have been triggered in their environment.

*P5: I think [challenging behaviour] it's a way of them communicating (...). There's something off, it upsets them. Like, for example, (...) we have young people who feel like certain smells could upset them. And then we find out later, after the de-escalation and calm them down, that it was something that the abuser may have used or had that smell. It comes up a lot.*

*P9: So sometimes they just get upset and get angry. And then they will resort to like aggression or self-harming (...) any little thing as well could trigger them like sometimes noise or someone saying something related to what they've gone through.*

Participants conceptualised some behaviours as a form of escapism or dissociation.

*P10: ...it's almost like to distance herself from the emotional confusion, she pretends she's somebody else.*

*P8: ...basically because they were doing drugs outside (...) I think that was that was a getaway for them really.*

Whilst other behaviours were understood to be a form of self-protection.

*P10: when they first came to us, they used to cover themselves in their own faeces and that was the behaviour that they developed before they came to us, to stop people going near them.*

*P4: It's like, you know, "I've been here, I've been punished. I've been burned" or whatever it is. "I'm ready. I'm up for it" Like, "no, you're not*

*going to do it to me now”, that's kind of what I've what I've seen, it's really, really sad.*

The impact of trauma was also discussed in terms of problems with psychological wellbeing.

*P1: You can see how all of that [traumatic experiences] has led to mental health. A lot of anxiety, really high anxiety...*

*P2: It affects them, their childhood, like, say, depression (...) It can cause mental health to them, from childhood.*

*P9: It could also be some of them will have anger issues and some of them going out in the community, will be like very anxious about it, doesn't wanna interact.*

The relational impact of trauma was discussed, participants noted the impact on relationships with staff.

*P3: You're just another person and I've heard it on multiple occasions. "I'm gonna break this placement down" So... "It's not even point getting to know you. What's the point?"*

*P10: When they come into a setting where people genuinely care, they cannot cope (...) it's almost like they don't know how to deal with- with people being nice to them and supporting them, because all they've known most of them, all they've known is...the touch of another human hurts.*

3.3.2.4. Summary: Few participants had specific training in trauma and some struggled to find the language to describe the impact of trauma or displayed a reductive understanding of what might be traumatic for YPWID. However, all participants considered behaviours and relational difficulties within the context of trauma and adversity and discussed the links they had observed.

3.3.2.5. Subtheme 3. Responding, Creating safety: In responding to the impact of trauma, participants highlighted their desire to make those they supported feel safe. They discussed how, when possible, they used knowledge of the young person's history to prevent distress, by tailoring practical elements of their support.

*P10: He was sexually abused by his foster father...so he cannot bear to have a male supporting him.*

*P9: The mother tried to drown them on the bath. So, if she were to have a bath, that pops up and instead she will always have a shower, which helps reduce that.*

Participants described how through building relationships with residents, they could embody a safe space.

*P8: I would always make sure they are safe with me, that they know that they're safe with me and that no one can come to their house (...) and do anything to them.*

*P4: Whenever he gets scared or (...) a bit unsteady, he runs and he stands and he holds my hand. I'm like, OK, I know that I'm the safe person. I think that's what it's all about. The relationships that we build with them and how we make them feel and that we have to be a safe support for them, because we are within their lives every single day...*

Relational safety was created through showing genuine care, listening, developing mutual respect and basing support around the young person's interests.

*P10: I said to him, "you know, we're gonna look after you, you're a part of our family now" (...) I said "we'll protect you and we will love you because you're part of our family now" and he cried (tearful).*

*P6: Some of them like just to have that closeness with somebody, to be able to, you know, if they're upset, receive a quick hug or, you know, just a stroke of the hand to say, look, we're- we understand. You know, we're working with you, we're gonna help you get through this.*

*P2: I focus on listening, accept their feelings and do not blame them in any way.*

*P3: "I'm here for you. Forget about I work for the company. Talk to me. What's annoyed you?" (...) I went to the person's room and say, "oh, you got a PlayStation? All right, let's play a couple of games" and then just sat down with them and played a couple of games. Now I formed the bond with you.*

*P3: She would express her views because I became a non-threat. I became a human being.*

Providing consistency and routine was also described as important in developing a sense of safety.

*P6: So, we were trying to...implement routine so they can see that it's consistent. They could have more stability (...) it's about trust.*

When supporting YPWID who cannot communicate verbally, participants described using body language and tone of voice to project safety.

*P5: So. like going into a more calm-stance type thing, or calm...chilled you. It works with them because then they're not...worried that something's gonna happen.*

*P6: A nice calming voice to bring down their mood (...) because they may be angry inside, if they're hearing another person that sounds angry inside, they will forever be angry.*



Whilst it was acknowledged that helping YPWID to feel safe took time, patience and persistence, and it was important to provide them with space.

*P4: It takes a lot of time to let them know that (...)“you're not the one that's not normal, the person that did to you,(...) is the one that's not normal. That's not how (...) people behave. You're safe”.*

*P3: I'm not going to push you, you'll come to me when you're ready, my door's open. I'm here.*

3.2.2.6. Summary: Creating a safe space was seen as an imperative part of support when responding to the impact of trauma and adverse experiences on the life's of YPWID. Participants described embodying safety through a process of building trust and relationships over time.

Subtheme 4. Responding, Moving forward and Resisting Re-traumatisation: In responding to trauma participants felt part of their role was to support residents to move on from the impact of adversity. They described ways they intended to support in this, even if this was not always possible within their working context.

*P9: I can't go back in time and - I wish I could- and change your father doing this to you or your mother doing that to you or this support worker doing that. I wish I could. It's not feasible. It's not possible. So what I can do is make the experiences that you have now...not make you forget, but not think about or dwell on those experiences.*

Developing relational safety was seen not only as a priority for care, but as a reparative process.

*P6: We want to show them how things can be done differently, how people can be trusted.*

*P4: ...a young girl that comes in and she's been sexually abused or physically abused by a man (...) It's so positive for them to then have that that model, that man in their in their life (...). We've got people that*

*are here for 10 years, and they've built all these relationships with people (...) it gives them a positive aspect.*

Management of challenging behaviour and supporting distress was a key topic for discussion. Many references positive behavioural support and focussed on procedures for de-escalation, risk management and distraction.

*P4: ...you'd pick up their folder, open that document and in that would be step-by-step how we would deal with that [behaviour], and how that's successful and how that works for that person*

This was also an area where participants described providing reparative relational experiences by using their knowledge to tailor their response to the needs of the young person, countering past experiences of rejection or neglect with emotional support and consistency, or providing space as necessary.

*P3: What he wanted to do is scare me to the point of me running away because he wanted to break down another service (...) we didn't show any fear in that situation (...) and then we started to form a bond. I said (...) you need anything call me (...) If I can achieve it, I'll help you.*

*P10: We try and connect much more on an emotional level (...) when somebody has a challenging behaviour, unless it is very risky (...) we let them express it (...) and once that behaviour has then run its course and they've calmed. "OK. What made you feel like that? What made you scream? What made you shout? What did you feel when that was happening?"*

*P7: It just depends on the child because some kids don't want reassurance. Some kids just wanna be alone, to regulate and take their feelings in.*

Participants described how a further aspect of moving on from the impact of adversity was supporting residents to access positive experiences, which could counter their negative experiences.

*P8: I think it [accessing activities] would be more of a distraction, really, and say that there is more good in this world than bad.*

*P2: The thing I think is important, we encourage them to practise in different...activities and play with one another (...) it will distract them and give them sense of normalcy.*

*P4: All my positive experiences have flushed out all the negative ones, you know, so trying to do that with these guys (...) We're going to do, you know, positive things, get you out, new memories, take you on holidays. That you've never done before...*

Although it was acknowledged that this was often not possible (as discussed in 3.3.1.1.)

*P4: ...but I think we can't, really. We don't really get to do that.*

Participants discussed the importance of considering the emotional needs of their clients, supporting them directly and through referral for specialist support.

*P9: ...it's about teaching them how to deal with their emotions once that comes up.*

*P1: It's us who have to say, we're concerned about mental health or we're concerned about anxiety. So, we're the ones who kind of pushed for referral, for therapy or things like that.*

Accessing specialist support could be a challenging process, participants described how residents might mistrust external services and described encouraging them to access support, whilst also ensuring services remained engaged.

*P9: Instead of talking to the mental health team, she rather speak to me. And then I'll have to communicate this to the mental health team (...) I*

*had to explain over and over [to the professionals] being patient with her, she might not come through now (...). So it got to a point there was no psychologist, just a psychiatrist and it will be between me and the psychiatrist all the time.*

As discussed, (3.3.1.1.), support was not always adequate. Two participants gave examples of advocating for a young person when they felt support from mental health services had not meet their needs, this was specifically relevant to issues with psychiatric diagnosis and medication.

*P3: I see this person on a daily basis, and you're telling me that that is 'behaviour' (...) No, I'm not accepting that. And I kept going (...) my team kept going and kept going (...) until it was reassessed, and medication was looked at (...). If you see that individual now to where they came from, you will not believe it's the same human being.*

*P9: If I'm telling you this is not working, this is what's happening. I'm expecting you to listen. We fought and fought.*

The potential for re-traumatisation within residential care was acknowledged. Providing a sense of safety, positive relational experiences and developing practical skills were discussed as important preventative measures.

*P7: Like if you don't provide...that sense of belonging or...safety...it could cause trauma (...) these kids have already been taken away from their families. Like we only want to make things better.*

*P3: You're not going to be in my care for the rest of your life, you might go to another home (...) where somebody, some support worker, it's just a job to them and they don't care, you know? So, you have...to look after yourself to a certain degree (...) what skills have we given you?*

3.2.2.7. Summary: Participants described their role in supporting YPWID to move on from trauma, through positive experiences, advocacy and facilitating

access to specialist support, though these practices were not always possible within their working context.

### 3.2.3. Theme 3. More Than a Job

Participants implied a sense of personal responsibility for their role. They discussed how fulfilling the role adequately required compassion and described the interaction between work and their personal lives. They acknowledged that the role required skill and suggested ways that they could be more valued.

3.2.3.1. Subtheme 1. Personal responsibility and impact: Participants described feeling a sense of personal duty and responsibility to their role, the personal impact the role could have on them and how they attempt to manage this. They described that exposure to the circumstances surrounding the young people and fears for their future wellbeing instilled a sense of duty to support and protect them.

*P3: Some of this stuff is so brutal and some of the stuff is so disturbing that you're like. I don't want to touch this with a...but...If I don't, then who will? Who does?*

*P6: I just want to help. I just want to make their situation better. I just feel a real need to, you know, be there for them to support them for everything.*

Participants discussed 'the right reasons' for being in the role. This was conceptualised as deeper than wanting paid employment, with genuine passion named as a necessary to be good RSW.

*P4: And I've always said that these jobs (...), people that don't have it in their hearts shouldn't do that (...) Like it's not something that you can just break in and out of. It's like you're in it because you want to be there not because you want your paycheck at the end of the month*

Due to the nature and requirements of the role, participants described developing strong, meaningful connections with YP.

*P1: I've known them for so long...they become like family.*

*P3: It affects me (...) You know, I've known you since 2015. I knew him till 2022. Seven years I've been that constant in your life.*

*P7: It's nice to be that person that they trust and have a sense of belonging with*

Navigating this attachment and maintaining professional boundaries was a concern for some participants.

*P1: Yeah, you've got some [staff] that struggle with boundaries (...) that get...a little bit too close.*

*P5: Yes, we're like the family, but then we have our (...) professional boundaries that we have to stick to as well.*

There were implications of a parental-type relationship, which could be evoked during behaviour management, with punitive or punishment-based methods, and RSW using personal values to guide their support.

*P4: And when they're going wrong, that's when they get reprimanded.*

*P6: I realised it was just her way of getting what she wanted. So, if- this client is a totally different client now (...) she was overweight (...) she's now her ideal weight.*

*P1: [discussing a 20yr old drinking alcohol] actually....is that a choice that we wanna be enabling?*

The bi-directional interaction between work and personal life was discussed. Participants described drawing on personal experiences of adversity, to assist in understanding the young people and their challenges.

*P5: I've got personal experience in that (...) I've got what they call complex PTSD from a lot of trauma in my life, so I've got the understanding of how it can affect the young people.*

Participants described the impact of the role on their personal life, including the personal reward associated with their role.

*P2: I enjoy interacting with the children, making them happy. I enjoy that very well. Whenever they are communicating with me, I love it so much.*

*P4: [caring for YPWID] that kind of changes your life as well as it you're changing other people's. They change yours as well.*

However, the role could also impact participants lives negatively. They described personal stress and overwhelm associated with day-to-day aspects of their role.

*P1: So you are enmeshed in in that house and that world (...) I think...It's emotionally draining. This type of work because it's all consuming*

*P10: But when you have a service user that first comes in, it's really daunting (...) when you say to somebody "They cover themselves in poo on a regular basis". As a carer you sit there and go "ohh my God, not only have I got to clean this up, I've gotta do multiple times a day? And I've got to do my documentation and I've gotta help clean the home and I've gotta do laundry? And I've gotta do cooking?" (...) It's like a bit of a mini explosion*

Fear at work and experiences of physical violence were common.

*P3. This young lady was so violent, I used to go home, my colleagues used to go home with scratches every single day, every single day.*

*P5: Well, you can't normally show that you are scared of them, because then they'll know that...you're an easier target, so you just have to put...a like hard face on type thing.*

Learning about the adversity residents had faced and witnessing their distress could have a negative impact, with implication for emotional distress.

*P3: I mean we hear some really disturbing things (...) if I thought about everything...I would break down and I would actually start to cry, you know.*

*P2: Sometimes I become so emotional(...) and then...sometimes I will be lonely for some time.*

*MW: You say you'll be lonely for some time. Do you mean be on your own for some time?*

*P2: Yes, to be able to pray.*

Challenging behaviours sometimes provoked difficult emotions in participants, which could lead to a desire to detach.

*P10: It's that difference between telling yourself "Not their fault". And "if I'm getting stressed, I'm the one that needs to walk away", instead of snapping.*

*P1: [describing YPWLD displaying frequent distress] I'm gonna be honest. It can become annoying (...) when I can see that that's not for genuine purpose, but then it's to illicit stuff that he hasn't had as a child.*

*P5: I stopped caring for that young person. It was...something in me that did not want to....get involved with that young person (...) It does regularly happen (...) So there is...emotions...in this job that we do.*

For these reasons it was hard for participants to leave their work behind when they left work, they discussed a desire to detach or compartmentalise for their own self-preservation.



*P6: Even when I go home, I'm still calling you back to making sure everything's alright (...) it's very hard to leave once you leave work.*

*P4: What I would probably choose to do differently is not be as emotionally attached (...) you have to learn how to separate work in your personal life.*

Participants described the importance of peer support in coping with the demands of the role.

*P5: If you have a nice support team behind you, you've got them who will support you in it. If you don't have it, then you know it's overwhelming.*

3.2.3.2. Summary: Due to the challenging system, demanding nature of the role and awareness of resident's trauma histories, participants described a sense of personal duty and the development of meaningful relationships with clients. They described the bi-directional interaction between their personal and work lives, including its impact on their wellbeing. They described the desire to detach to mitigate the negative impact of the role and the value of peer support in resisting the challenges imposed by the system.

3.2.3.3. Valuing RSW. Participants acknowledged the complexity of the role and discussed how more value should be placed on the work they do.

There was implication that participants were aware their role requires significant skill.

*P3: Let me do what I'm good at. And you do what you're good at. And between the two of us, we can cover a variety of different avenues.*

*P6: We get the clients with the more complex needs. So, they don't just have autism, they have autism...challenging behaviour (...) all different kinds of illnesses (...) So we're the ones that manage all those.*

They discussed that the role should be more valued by society, by external services and within their own organisation.

*P6: ...the only thing that I would...like to see is that...us as support workers...are recognised a bit more (...) because...we do a lot of work, a lot of work, and when I tell you the...challenging behaviour clients are very hard work (...) We're not recognised as much as staff that are working with the NHS.*

*P10: I genuinely feel that carers should be registered.*

They described various ways external services could demonstrate value for their role and in turn provide better opportunities and care for the YPWID they support. A key way was through external services listening to RSW.

*P6: Us as support workers, we're with them day-to-day. Caring for their needs and we could advise a bit more. You know, to show OK, if they behave in this certain way, how we manage this situation.*

*P3: One of the things that work is when people are listened to, you know (...) If you don't give me the support I need now, there's going to be hospitalisations which cost more (...) the person who suffers is the individual that we're all looking after.*

*P9: You have to listen to the key worker (...) So if you're not listening, you're just taking whatever another medical person wrote, a note, you won't have anything to put forward to say, OK, this is what we're going to do, you know.*

They described how their organisation could demonstrate value through recognition and better-quality training.

*P9: There's something called incentives (...) So, like rewards and you know when you do the best you can, they acknowledge you (...) things like that will motivate the carers as well.*

*P2: By giving we more training. Obviously, we are this people taking care of them (...). So by giving us more training, to have more knowledge*

*P10: I would love to see very specific mandatory training for any new carer, no matter what their age, that are coming into this setting. Because working with people with autism and learning disabilities is so complex.*

The need for pay to reflect the level of work, their skills and experience was also highlighted.

*P6: Up our wages. I don't think we get paid enough to be fair, for what we do*

*P7: This girl got her fingers broken the other day for like 50p over minimum wage and I'm like...is it worth it? Do you know what I mean? Like I'm going to have a Masters in January and I'm like...why? Why am I still here?*

3.2.3.4. Summary: Participants discussed the complexity and challenges of their role and ways the value of their role could be acknowledged through external services listening to RSW, through better quality training and through pay which reflects the complexity of the role.

#### **4. DISCUSSION**

This is the first research to explore RSW insight into supporting YPWID who have experienced trauma. The study aimed to explore how RSW understand and respond to trauma in YPWID, alongside barriers and facilitators to support, with view to understanding how to upskill community services in trauma-informed practice. This chapter will initially answer the first four research questions set out in the Introduction, discussing relevance to current literature. The fifth research question is answered in the implications section, alongside

discussion of wider implications and recommendations for future research. A critical appraisal of the study will be provided including strengths, limitations and reflexivity.

#### **4.1. Research Questions and Summary of Findings**

##### **4.1.1. What Do RSW Understand About the Impact of Traumatic Experiences on YPWID?**

Despite few participants reporting training in trauma, they demonstrated a broad understanding of the impact of trauma on those they support, as evidenced in theme 2.2. *Recognising the impact of trauma.*

Many participants initially struggled to discuss the causes and perceived impact of trauma, showing difficulty finding language to demonstrate their understanding, or diverting away from the topic. Lack of specific training, which could provide the language and context for discussion of trauma, could account for this. This is supported by Truesdale et al. (2019) and their research on ID healthcare professionals. A further possible reason, as suggested by Furnivall et al., (2007), is that trauma is a normalised part of resident's experience, so it is not often considered and discussed explicitly. Difficulty discussing trauma could also be considered as a factor of routine avoidance which RSW engage in, to avoid distress associated with thoughts of trauma that YPWID have experienced (Goad, 2021). RSW in this and other studies explicitly discussed significant distress associated with considering the trauma that young people face, and this is well supported in the literature (Abraham et al., 2022; Furnivall et al., 2007; King et al., 2022; Kor et al., 2021; McElvaney & Tatlow-Golden, 2016). As a workforce who do not receive routine clinical supervision or support around the emotional impact of their work, avoidance of thinking about and discussing trauma may be an adaptive and necessary response to protect personal wellbeing and remain in work, however it has implications for those they support.

Despite these initial difficulties, with space for reflection all participants were able to demonstrate knowledge of the causes and impact of trauma in YPWID,

with many demonstrating a sophisticated and in-depth knowledge, which was an unexpected finding relative to the literature base. Although three participants had studied psychology at university level, the most sophisticated understanding was exhibited by participants who had more years of experience in the role. This finding may reflect an increase in awareness of psychological language, such as 'trauma' and themes around trauma across the media in recent years. It may also be that experience of trauma is more salient in child ID settings than in adult settings, due to recency of traumatic events. It is also likely that providing participants dedicated space for reflection on their clients within the context of trauma was a crucial part of helping them to reflect and make links between their knowledge of trauma in the general population and the young people they support.

4.1.1.1. Causes of trauma: Trauma was most commonly discussed in relation to abuse, Keesler (2014), reported similar findings amongst service co-ordinators. This is unsurprising given that few RSW had received specific trauma training and is likely to reflect narratives perpetuated by mass media. However, a narrow focus on abuse neglects wider adverse experiences YPWID face and may have implications for which behaviours and psychological problems are understood to be trauma related. However, throughout the interviews many RSW also implied knowledge of a range of broader adverse experiences, including discrimination, loss, and those related to disruption in attachment with families and staff. This reflects the findings of McNally et al., (2021) and suggests that by being given space to reflect and consider YPWID's experiences, behaviours and support needs, RSW without the language of trauma literature still demonstrate a broad knowledge of the impact of trauma.

4.1.1.2. Impact of trauma: It was described that some YPWID may experience increased trauma related difficulties due to cognitive impairment. This is supported by studies describing that reduced cognitive capacity increases susceptibility to development of PTSD (Delhalle & Blavier, 2023; Martorell et al., 2009) and reflects the understanding of RSW in one other study (Gray & Abendroth, 2016). In line with the evidence base (Kildahl et al., 2020a; McCarthy et al., 2017; McNally et al., 2021), RSW described that trauma could impact YPWID's behaviour, describing that challenging behaviour could be

displayed when YPWID struggle to cope with emotional difficulties related to their experiences, as a way of communicating distress, for escape or self-protection. In contrast to McNally et al. (2022), many RSW in this study were able to link behaviours to specific traumatic experiences, which may be related to relative recency of traumatic experience in this younger client group. In two previous studies RSW and mental health clinicians acknowledged reduction in behaviours and loss of function as a result of trauma (Gray & Abendroth, 2016; Kildahl et al., 2020b), this research did not replicate these findings. Again, this is understandable within the context of lack of training, but may also point to the impact of high workloads with multiple competing demands, meaning RSW's attention is more likely to be captured by behaviours involving direct risk.

Trauma experiences were also linked to reduction in psychological wellbeing in YPWID, this is reflected in the broader literature (Emerson & Hatton, 2007; Stathopoulou et al., 2018), and in previous studies exploring knowledge of RSW and other professional stakeholders working with adults with ID and care-experienced children (Gray & Abendroth, 2016; Keesler, 2014b; Kildahl et al., 2020b; McNally et al., 2022; Truesdale et al., 2019). The relational impact of trauma was discussed in terms of problems building relationships with staff and services and demonstrating 'attention-seeking' behaviour, highlighting the importance of attachment-focussed approaches to supporting YPWID in residential care (British Psychological Society, 2017; Lyons-Ruth et al., 2009).

#### 4.1.2. How Do RSW Think They Can Best Support PWID Who Have Experienced Traumatic or Adverse Life Events?

RSW described various ways they felt they should support YPWID who have experienced trauma, this included building a picture of their history, as evidenced in theme 2.1. *What has happened to you?* They also described how they seek to respond when they are aware of trauma history, through an emphasis on safety as evidenced in theme 2.3 *Responding: Creating Safety* and through supporting YPWID to move on, as evidenced in theme 2.4. *Responding: Moving Forward*. Finally, they emphasise the importance of services listening to them, so YPWID get the support they need, as evidenced in 3.2. *Valuing RSW*.

4.1.2.1. What has happened to you? Participants expressed awareness of the prevalence of trauma and described informal assessment as crucial for support, in line with the values of TIC which emphasise the importance of asking 'what has happened to you?' (McNally et al., 2023; SAMHSA, 2014). The current study identified that knowledge of trauma impacted the way that RSW interpreted behaviours, increasing compassion with implications for the support they provided and their experience of their role, strengthening arguments to integrate TIC into ID services (Beail et al., 2021; Keesler, 2014a; McNally et al., 2023).

Participants described engaging in a complex process of information gathering to understand the history and needs of the YPWID they support. This included; attempts to gather historical information from services; observing behaviours and talking to YPWID, where possible. Previous studies have reported staff in adult ID services engaging in similar processes of informal assessment (McNally et al., 2022), though this was not reflected in the (non-ID specific) child residential literature. This may be related to the medicalisation of ID and ideological barriers which have prevented knowledge development of trauma in the ID population, meaning trauma experiences are less likely to be acknowledged and trauma-related needs are less likely to be assessed and communicated by professional services. Healthcare professionals discussed the complexity of assessing trauma in ID populations, linked to diagnostic overshadowing, complexity of presentation and difficulties PWID may face in communicating what has happened to them (Kildahl et al., 2020b; K. Simpson et al., 2022), whilst YPWID may be even less able to identify and report abuse themselves and there may be a greater likelihood of abuse of YPWID being dismissed (Cooke & Standen, 2002; K. Simpson et al., 2022). Kildahl et al., (2020) also suggested that mental health clinicians must adopt a specific trauma-focus to identify trauma in PWID and many described overlooking trauma. The evidence from this study and McNally et al. (2022), tentatively suggests that failure of services to acknowledge trauma in ID means that RSW are required to undertake the complex task of investigating trauma histories, to meet the needs of those they support.

4.1.2.2. *Creating Safety*: Creating safe physical and relational environments was another key element of support, a theme which was reflected in research with staff in adult ID and child residential services and by various stakeholders (Keesler, 2014b; McElvaney & Tatlow-Golden, 2016; McNally et al., 2022; K. Simpson et al., 2022) and is in line with the principles of TIC (McNally, 2022; SAMHSA, 2014). Participants described how they would use knowledge of trauma to adapt the environment and prevent reminders of trauma. There was also a strong emphasis on relational safety and building attachments with YPWID through showing genuine care, consistency and attunement to their needs, a theme emphasised in research with social workers working with this population (K. Simpson et al., 2022). In this study, when working with young people with severe ID, RSW described projecting safety through body language and tone of voice, demonstrating sophisticated communication skills and awareness of the emotional and relational needs of the YPWID they support. The fostering of safety, and particularly safe relationships, is supported as a key healing mechanism in both attachment literature and neurodevelopmental models of trauma. It is thought to enhance coping and strengthen neural circuits which support social engagement and downregulate threat sensitivity and defensive mechanisms, whilst the use of body language and tone of voice is additionally recommended for professionals in the treatment of trauma in children (BPS, 2017; Porges & Dana, 2018; Tronick et al., 1977; Tucci et al., 2018).

4.1.2.3. *Moving forward*: Participants described a further aspect of support was to help YPWID to move on from their traumatic experiences. They described doing this through modelling healthy relationships, and accessing community and recreational activities which they felt could be reparative, countering negative experiences. RSW in adult ID services also described general support as a form of trauma intervention (McNally et al., 2022). This approach appears to be in line with cognitive-behavioural models of treating psychological distress, which emphasise how difficult thoughts and feelings may be changed through positive experiences (Kennerley et al., 2017). It is possible that RSW have developed this perspective through the past implementation of care plans based on such models, continuing to employ these ideas in the absence of alternative trauma-focussed models. It is also understandable that RSW would



want to involve YPWID in a range of social and community experiences where possible, and this is likely to have many benefits for social and emotional development. However, increased trauma awareness may be useful in understanding barriers to this approach or why it may not always alleviate distress or fear.

Management of challenging behaviour was a common topic and whilst many RSW described practices linked to positive behavioural support (BILD et al., 2017), there was a view that this was an area in which RSW could provide relational experiences to counter maltreatment. Meeting challenging behaviour with emotional support, empathy and a focus on security, alongside legitimising the right of PWID to be distressed an important aspect of preventing re-traumatisation (McNally, 2022; SAMHSA, 2014).

Participants described a further aspect of support as identifying the mental health needs of their clients and requesting support. Whilst this part of the role was acknowledged by other RSW (Furnivall et al., 2007; Gray & Abendroth, 2016; McElvaney & Tatlow-Golden, 2016), a small number of participants in this study went on to describe engaging in a complex process to secure and sustain mental health support when met with resistance from both services and young people. This included attempts to convince services to remain engaged when individuals were resistant to support, because of mistrust related to past experiences with services or attachment-related trauma. Participants described a challenging process of advocacy when treatment did not meet the needs of the young person. This form of advocacy may be an important experience of YPWID, as having mental health needs overlooked or dismissed can re-traumatise individuals with trauma histories (SAMHSA, 2014). In addition, timely and appropriate mental health support in childhood is described as a priority by adults with ID, who have experienced trauma (Wilczek, 2021), as well as in social equality literature (Marmot et al., 2020; WHO, 2014). Keesler et al. (2014), described that in the absence of family networks, residential services often play a crucial role in facilitating inter-agency communication, advocating for PWID and securing specialist support. Surprisingly in this study, despite the age of the YPWID, families were rarely mentioned and often only in the context of abuse. In line with participants reports of minimal Social Care involvement, it

seems this means the organisation may be required to take on the role of advocating for and facilitating appropriate treatment. Given the demanding nature of the role, multiple competing demands and lack of specific training, it is likely that for many RSW this would not be possible, potentially resulting in YPWID having their mental health needs overlooked.

Though only a small number of participants mentioned re-traumatisation explicitly, there was broad acknowledgement that creating safe relational environments and supporting with skill development could protect against further mistreatment within the care system, demonstrating beliefs that align with the principles of TIC (SAMHSA, 2014).

4.1.2.4. Listening to RSW: A strong theme was the need for external services to listen to RSW and value their input. Participants acknowledged that they spend the most time with residents and so are best placed to identify and comment on behavioural and emotional changes, emphasising that services listening to them would enable YPWID to receive the support they need. Mental health clinicians and Social Care professionals have also emphasised the need to involve RSW in assessments, describing that they may be best placed to identify trauma-related challenges (Kildahl et al., 2020b; K. Simpson et al., 2022).

#### 4.1.3. How Does this Fit Within Service Context?

To answer this question, barriers and facilitators to support will be explored. Barriers were most frequently discussed, a strong theme was a working context which embodied experiences of trauma at various levels, 1 '*Trauma in the System*'. Participants described subjugation that YPWID face in the community, meaning lack of access to activities as evidenced in 1.1. *Invisible in the community*, alongside a sense of abandonment by external services, as evidenced in theme 1.2. *Abandoned by services*. Participants described barriers at the organisational level, including staffing issues, the demanding nature of the role, lack of time, resources and training to support YPWID in the way they would like, as evidenced in theme 1.2. *Organisational stress*. A further barrier was the emotional impact of the role, resulting in a desire to detach, as evidenced in 3.1. *Personal duty and impact*. Throughout, small numbers of

participants highlighted examples of good practice which facilitated support, including good inter-agency working, training and supportive teams.

*4.1.3.1. Lack of community accessibility:* Participants expressed a desire to help YPWID to move on from trauma through accessing new community and social experiences. However, they described an impervious community context, with discriminatory attitudes, funding cuts limiting higher education opportunities and lack of accessible spaces for recreational and social activities. This was linked to increases in challenging behaviour, psychological distress and limitations to relationships. Such discriminatory experiences have been well documented in the critical disabilities studies literature (eg. Oliver, 2013). Despite public awareness of the Human Rights implications, and policies which have sought to address this (Barnes, 2020), this evidence suggests that YPWID continue to experience oppressive community environments which have been discussed as potentially traumatising in themselves (Lopez et al., 2021), and are likely to limit their social and emotional development, with implications for poor health and wellbeing outcomes into adulthood (Emerson & Gone, 2012).

*4.1.3.2. Poor inter-agency working:* This barrier was echoed across the literature. Participants described external services which did not share information, were hard to access, did not listen to the views of RSW and provided support which was not tailored to the needs of YPWID. Poor information sharing limited RSW's ability to understand trauma-related difficulties and develop support plans. Kor et al. (2021), described that poor inter-agency information-sharing practices could lead to retraumatisation within the residential care system. Participants the present study described that poor information-sharing could be related to competing priorities, particularly in terms of hospital discharge. This provides an example of how policies and targets aimed at reducing inpatient care (NHS., 2019, DoH., 2012, DoH., 2015), might lead services to push for discharge regardless of its appropriateness, evidencing the need to both enhance the capability of community services to care for YPWID with complex needs, but also for system-wide understanding of the traumatising effects of placement instability.

Participants described their own experiences of subjugation by external services, feeling under-supported in meeting the complex needs of YPWID who have experienced trauma, describing a sense of abandonment or neglect, mirroring the trauma response of those they support. In child residential services, McElvaney & Tatlow-Golden (2016) described instances of RSW 'going into battle' to access support for clients, and high levels of gatekeeping by services. In this study, when support was accessed, participants described feeling dismissed by professionals not valuing their input, and being asked to implement care plans and strategies which were not possible within the service context and did not meet the needs of YPWID. Mental health professionals have described the inherent challenges in behavioural interpretation and variability given potential of day-to-day changes in presentation, meaning there is an increased need to involve RSW in multi-level assessments to reveal, understand and treat trauma-related behaviours (Kildahl et al., 2020). Not doing so may lead to inadequate support, missed information, withdrawal of support or support plans that do not account for individual needs and what is feasible in the organisational context. Kor et al. (2021), also described RSW feeling that care plans were unrealistic, meaning RSW were left to adapt the support plan to meet client needs. Although there may be many cases where RSW do this sensitively and successfully, RSW taking care plans into their own hands in the absence of clear guidance has been implicated as a risk for malpractice within children's residential services (CDC, 2022) and it is concerning that some RSW may feel they have no choice.

The reported failings of the system to acknowledge and respond to trauma in YPWID may be a factor of the medicalisation of ID (Barnes, 2020), leading to diagnostic overshadowing (Mason & Scior, 2004), which affects professionals perceptions of what may be a manifestation of psychological distress rather than part of ID. Mental health and Social Care professionals have discussed barriers to support, including lack of available treatment options, complex, time-consuming assessments and lack of professional knowledge of trauma in PWID (Keesler, 2014b; Kildahl et al., 2020b; K. Simpson et al., 2022; Truesdale et al., 2019). Alongside long waiting lists, staffing issues and time constraints, lack of confidence and competence in working with the level of complexity these young people may present with may lead towards an avoidance on the part of some

professionals, further perpetuating systemic abandonment and traumatisation. Due to inherent power imbalances between RSW and external professionals, it may also not feel viable for RSW to challenge their input.

4.1.3.3. Organisational Stress: At the organisational level, many participants described a stressful context. Staffing and recruitment issues were a common theme which impeded RSW ability to fulfil their role. It was clear how organisations could become stuck in cycles of poor recruitment and retention. Poor staffing increased the pressure in this already complex role, leading to high levels of resignation, meaning organisations recruit inexperienced staff, who without adequate support were less able to deal with the demands of the role and who also often quickly resigned. Such staffing pressures generate a context where RSW were less able to support YPWID emotionally and were left feeling stressed, overwhelmed and undervalued. High staff turnover in children's residential services has been highlighted in the literature for many years (Colton & Roberts, 2007), with implications for further attachment disruption of YPWID and loss of knowledge across teams.

Participants described the value of experienced colleagues as a facilitator for support, which has been reflected in other studies (Abraham et al., 2022), however experienced colleagues were said to be resigning as they could no longer cope with the role's demands. Addressing staffing issues has been highlighted as a national recommendation for UK government (CDC, 2022), who have committed to exploring options for workforce development (DfE, 2023).

A further organisational barrier was lack of resource, this directly affected the quality of support, e.g. RSW being unable to take their clients on trips. Participants also reported poor information-sharing within the organisation, one highlighted this was possibly to prevent staff panicking around the complexity of cases. In some cases there may be details which are not appropriate for all staff to know, however in the care of PWID who have experienced trauma, guidance emphasises that staff should know them well, including their trauma history and this should be incorporated into their support plan (Beail et al., 2021). By neglecting to share information upon entry to service, managers subject RSW to

situations where they do not have the necessary information to interpret behaviours and provide sensitive and appropriate support, posing risk for poor care practices and safety of YPWID and RSW, resulting in low job satisfaction and staff burnout (Ryan et al., 2021, CDC, 2022).

Training was another barrier to RSW completing their role as desired. Participants expressed dissatisfaction at the quality and quantity of training, describing that whilst they were required to identify mental health needs in YPWID, they felt under-skilled and under-supported in this area. It is likely that the systemic and historical dismissal of the mental health needs of YPWID has led to their de-prioritisation within organisational culture. Similar findings have been reported in adult ID services (McNally et al., 2022), professionals have described inadequate staff training in trauma as a barrier to compassionate support (Truesdale et al., 2019), and training has been highlighted as an urgent priority for child ID workforce development (CDC, 2023).

As well as directly impacting the support of YPWID, these factors, alongside poor pay, led RSW to feel undervalued by their organisation, likely compounding the staffing issues and acting as a further barrier to support.

4.1.3.4. Emotional Impact: A further barrier to support was the emotional impact of the role, which some participants described could lead to a desire to detach from their clients. These findings have been demonstrated in previous research into RSW experience working with trauma, as staff describe feeling emotionally unavailable to clients due to the demanding nature of their role (04/09/2024 13:10:00 Abraham et al., 2022). Both burnout and vicarious trauma have been linked to detachment and depersonalisation of clients, with implications for reduced quality of care, inconsistencies in support and neglect of client needs, posing serious risks to safety and development, decreasing job satisfaction and compromising staff's ability to maintain ethical standards and boundaries (Maslack & Jackson, 1981, Figley & Ludick, 2017).

4.1.3.5. *Facilitators*: Small numbers of participants described facilitators to support, including good inter-agency working, feeling valued and quality training. Engaging in peer support was an additional facilitator which helped

RSW cope with the demands of their role and acted as a resistance against the lack of value placed on them by their organisations, external services and society. Abraham (2022) also described the discrepancy between mutual support within teams and the lack of value placed on the role by society. It is suggested that RSW may seek a sense of value and belonging through peer support in the absence of professional identity and recognition, and this has been described as a mediator against burnout (Parry et al., 2022).

#### 4.1.4. What is RSW Experience of Supporting YPID Who Have Experienced Trauma?

The complex, emotionally and physically demanding nature of this work has been described throughout the analysis. Participants discussed the impact of these challenges on their emotional wellbeing and personal life, also emphasising a profound sense of personal duty and responsibility to the role, describing that fulfilling their responsibilities effectively necessitates genuine, compassion, also discussing the rewarding aspects of the work, as evidenced in theme 3.1 *Personal responsibility and impact*. The sense of hopelessness around the systemic barriers described could also be conceptualised as a form of moral distress, as evidenced in themes 1.1. *Invisible in the community* and 1.2. *Abandoned by services*.

4.1.4.1. RSW Wellbeing: The quality of care that RSW provide is in part determined by their wellbeing. In this study participants described experiencing overwhelm and stress associated with the demanding nature of their work, and fear associated with challenging behaviours and physical violence. Exposure to challenging behaviour in services for YPWID has been associated with poor staff wellbeing including PTSD-like symptoms (King et al., 2022), and burnout (Ryan et al., 2021). Distress was also associated with bearing witness to the adversity clients had experienced. Similar experiences have been reported across child and ID residential services and have been linked to burnout and vicarious trauma (Audin et al., 2018; Ryan et al., 2021; Baker et al., 2019).

Research has long reported that working with trauma survivors can have a serious impact on supporters, through unrelenting exposure to accounts of adverse experiences and their impact (Beail, 2021). RSW have more exposure

to challenging emotions and behaviours than management or external professionals (Furnivall et al, 2007), however many also receive little formal support, meaning they may struggle to process and make sense of these experiences, with implications for their health and wellbeing. Though participants were not asked about trauma in their own history, some volunteered this information. It is understood that many RSW report increased levels of ACE's and RSW in ID services are thought to be particularly vulnerable to re-traumatisation, through high levels of exposure to challenging behaviour and complex needs (Keesler, 2018), emphasising the need for structured supervision and support.

Operating within the context of a dysfunctional system, participants described feelings of stress, hopelessness and mistrust of services, importantly RSW are also implicated in this system which serves to re-traumatise the YPWID they are tasked with supporting. A moral event is one in which the accepted response is unavailable (Morley et al., 2019), and many examples of moral events were given, for example in having to build a picture of the young person's life in the absence of quality historical information, in being unable to provide the support they want to due to being poorly staffed, under-resourced or because activities are inaccessible, in feeling under-skilled supporting residents who remain on waiting lists for specialist support and in attempting to deliver care plans which do not meet resident's needs. Whilst these issues are systemic, they are all incidents where RSW are complicit in the harm caused or perpetuated by the system. The 'moral-injury' (Jameton, 1977), related to this has been associated with high rates of staff sickness, desire to resign and psychological distress and is likely to be layered with the effects of vicarious trauma and burnout with severe implications for the workforce, organisations and residents (Brend, 2020).

4.1.4.2. More than a job: Participants described a sense of personal duty and responsibility towards their role, likely related to an awareness of adversity that faced by residents, alongside the knowledge of systemic failures to support YPWID and absence of family involvement; with similar findings described in Social Care professionals working with adults and children with ID (Simpson et al., 2022, Keesler, 2014). A further factor could be personal experiences of



ACEs, as research has found many people who have experienced ACEs are drawn towards helping professions (Keesler, 2018).

In this study, participants commonly emphasised that RSW should be in their role for 'the right reasons', primarily genuine care for residents. While a strong sense of duty and commitment to the role could be seen as beneficial, it could be damaging without adequate support and supervision, particularly in cases where RSW have their own experiences of adversity. This could also make it difficult to maintain boundaries with struggling organisations increasing risk for emotional exhaustion and burnout.

4.1.4.3. Relationships: This level of responsibility, care and absorption in the workplace led to the development of strong, meaningful relationships with clients, with many participants describing them as alike to family. As discussed, consistent and caring relationships are likely to be a key feature of healing for traumatised YPWID (BPS, 2017), however such deep connections to residents without appropriate supervision may not always be advantageous. Many RSW described difficulties detaching from work and noted that their role impacted their personal life. Difficulty detaching from work was also a theme amongst RSW in other research (Mcelvaney & Tatlow-Golden, 2016, Abraham et al., 2022) and has been associated with vicarious trauma in residential services (Audin et al., 2018), further evidencing the need for structured support for RSW. It could also impact the quality of care they provide, as they become more likely to impose their personal values on those they support, contrasting principles of person-centred care (Barr et al., 2020).

4.1.4.4. *Rewarding Role*: Despite the various challenges associated with this work, all participants described their role as rewarding, they described positive emotions related to interacting with clients and seeing them progress and one described that the role had positively changed their life.

#### 4.1.5. Summary of findings

These findings add to the literature in its exploration of how RSW understand and respond to trauma in YPWID, addressing the intersection of trauma, intellectual disabilities, and residential care in a younger population.

The findings provide evidence that supports the importance of trauma-informed approaches in residential care settings. It also emphasises the systemic barriers that have been noted in broader TIC literature, such as poor inter-agency collaboration, lack of resources, and insufficient staff support, and how this impacts both residents and staff. The study also builds on the idea that frontline staff play a crucial role in the implementation of TIC, a concept emphasised in other studies focusing on children's and ID services.

In contrast to previous literature, despite minimal training, participants demonstrated a sophisticated insight of the impact of trauma on YPWID and expressed the desire to support these young people in ways relevant to attachment and trauma-focussed literature, suggesting trauma-informed care will be well received by RSW. Findings also highlight how systemic challenges impact RSWs working with this specific population, emphasising that RSWs in these settings may experience greater stress and fewer supports than those in other care contexts. It was found that the nature of their work, alongside systemic challenges they face lead to a sense of personal duty and high levels of workplace absorption, also revealing the high level of advocacy required to ensure residents access support to meet their needs. This suggests that existing TIC models might need adaptation to account for the specific needs of YPWID and staff to be effective in this specialised environment.

## **4.2. Implications**

YPWID are some of the most vulnerable individuals in society. Those in residential care, who have experienced trauma or adversity, are likely to have specific needs which must be addressed to support their social and emotional development and psychological and physical wellbeing into adulthood.

Evidence here and in other research has shown the complexity involved in providing day-to-day support for these young people, and the physical, emotional and personal nature of this work. However, those tasked with providing their daily support are under-valued in terms of status and wages and

many feel unsupported by their organisations and professional services, leading to high levels of staff turnover which has serious consequences for the workforce and ultimately those they support. Society has a duty to support these young people and in doing so, must address systemic barriers to support, and the needs of their supporters. This section answers the final research question, describing implications of the research and evidence for the implementation of TIC at the clinical, service and policy level.

#### 4.2.1. Clinical Implications

4.2.1.1. *Supporting RSW*: By understanding the experience of RSW in supporting YPWID who have experienced trauma, this research has added to a body of literature highlighting the need for support for RSW, describing specific need related to working with YPWID who have experienced trauma.

A key factor highlighted in this and other studies as conducive to staff wellbeing is organisational support (McNally et al., 2023; Ryan et al., 2021), Clinical psychologists can support organisations by highlighting key ways which they can help RSW feel supported:

- Acknowledging achievement
- Ensuring staff safety
- Providing debriefs following incidents
- Listening to staff views
- Sharing information
- Creating processes to attend to staff wellbeing

A unique finding In this study was that RSW were able to use the interviews as a reflective space which helped them connect experiences of adversity with its impact on YPWID and themselves, whilst findings also highlighted the value of peer-support. Clinical psychologists may therefore seek to support services in implementing reflective peer-support groups. Reflective practice models have been developed for use in healthcare settings, with focus on supporting staff to develop individual and group reflective practice, enhance peer relationships and support collectivist approaches, fostering staff empowerment (Kurtz, 2020).

4.2.1.2. Training: Whilst participants demonstrated good basic knowledge on the causes and impact of trauma in YPWID, specific training would be advantageous to ensure all RSW have a thorough understanding of trauma, extending beyond 'abuse'. Key areas of development are the impact of wider socio-ecological factors such as discrimination and poverty, the relation of trauma to health problems and reduction in function, as these were not commonly acknowledged.

#### 4.2.2. Service Implications

4.2.2.1. *Implementing TIC*: TIC helps organisations to recognise trauma, respond appropriately and resist re-traumatisation of clients and staff (SAMHSA., 2014). Findings here suggest the implementation of TIC may be advantageous for services and YPWID, as it addresses the following organisational-level barriers to support (Goad, 2021; McNally, 2022):

- Safety: TIC prioritises safety of staff and clients, emphasising that relational safety of staff is key in providing effective support.
- Feeling valued: TIC requires transparency and trustworthiness in organisations, acknowledging that YPWID may struggle to build trust with services, whilst addressing the need for organisations to value RSW through information sharing and recognising opportunities for staff growth, with implications for wellbeing and retention.
- Listening to RSW: TIC promotes informed choices and shared decision making for staff and clients, fostering a sense of value amongst RSW and residents, whilst allowing RSW to suggest relevant changes for wellbeing of staff and clients.
- Preventing re-traumatisation: TIC acknowledges the relevance of trauma and adversity for clients and staff. Preventing re-traumatisation through acknowledging and responding to the trauma related needs of clients and through an organisational focus on staff wellbeing.

Additional recommendations from this study include:

- Attachment and relational security: A focus on developing secure attachment may be particularly relevant for YPWID in supporting long-

term physical and psychological health. This could include defining a safe and supportive 'family' environment within residential care and outlining staff and organisational responsibilities for delivering this.

- Ordinary Childhood Activities: Allocate resources to ensure YPWID access to typical childhood experiences, considering these as instrumental in addressing trauma's impact and preventing re-traumatisation.

Implementation of TIC in ID services requires a supportive organisation and a shift whereby the values of TIC are prioritised throughout organisational culture (Goad, 2021). Based on interviews with staff and PWID, McNally (2022) created a framework for the implementation of TIC in residential ID services, which aligns with principles of positive behavioural support that are commonly used in services, also evidenced in this study, and clinical psychologists may be well placed to support organisations in implementing this. Evidence here indicates TIC will be well received by RSW, who exhibit many aligning values and commitment to the wellbeing of YPWID. However, findings suggest that for TIC to be effective in residential organisations, changes must occur throughout ID services and at a policy level.

4.2.2.2. Inter-agency working: Findings suggest poor inter-agency working as a key barrier to support for trauma in YPWID. Services may seek to better meet the needs of YPWID in the following ways:

- Assess trauma needs on entry to the care system: Develop standardised multi-level trauma assessments as part of standard support pathways for YPWID.
- Prioritise information-sharing: Share historical and contextual information to help residential services meet YPWID's needs.
- Value and listen to RSW: Professionals must acknowledge RSW as essential stakeholders, often operating within a context of high stress, with limited support. They must seek to capture RSWs views and expertise, provide psychoeducation as appropriate and collaborate on care plans.

- Consider systemic barriers: Professionals have cited the need to train RSW (Truesdale et al., 2019), with little recognition of barriers which they face. Professionals must acknowledge that trauma training alone will be insufficient in the context of a dysfunctional system and should seek to address systemic barriers.
- Address power imbalances: Acknowledge power imbalances between professionals and RSW, make effort to redress these barriers and promote collaborative working.
- Acknowledge avoidance: It has been considered here that poor inter-agency working and lack of support could in part be a factor of avoidance, as some professionals feel ill-equipped to support the needs of YPWID who have experienced trauma. Evidence here shows that if professionals do not provide support, whilst RSW may do their best to advocate or adapt support plans, they are often unable to support YPWID effectively alone.
- Commit to professional development: Whilst the evidence base on the impact of trauma in YPWID is still emerging, the evidence that exists warrants serious consideration. Professionals should regularly review training needs, use professional power to dismantle ideological barriers, such as the medicalisation of disability, and maintain awareness of diagnostic overshadowing.

4.2.2.3. Overcoming Barriers. A stepped approach to implementation: Many similar recommendations have been highlighted elsewhere; however there are often barriers to implementation of TIC (e.g. Goad, 2021). Considering the recommendations here, the following stepped approach may be advantageous for implementing TIC within residential settings for YPWID:

#### Step 1: Organisational Assessment and Preparation

- Assess the current state of the organisation's culture, policies, and practices to identify gaps in TIC
- Secure commitment from senior leadership

- Establish a multidisciplinary team, including clinical psychology, to lead the TIC implementation, ensuring representation from all levels of staff, including RSW.

#### Step 2: Staff Training and Development

- Provide foundational TIC training to all staff, including specific modules on attachment and relational security for YPWID.
- Regularly assess and address the training needs of staff, offering advanced training on trauma, disability, and systemic barriers.
- Develop initiatives to recognise, value, and support RSWs.

#### Step 3: Policy and Practice Integration

- Align organisational policies with TIC principles.
- Implement standardised trauma assessments as part of the care pathway for YPWID upon entry into the system.
- Ensure that resources are available to provide YPWID access to ordinary childhood activities, crucial for their long-term well-being and trauma recovery.

#### Step 4: Inter-Agency Collaboration

- Establish protocols for sharing historical and contextual information between agencies to better meet the needs of YPWID.
- Foster inter-agency collaboration by addressing power imbalances and ensuring that RSWs' expertise and perspectives are valued and integrated into care plans.
- Identify and work to dismantle systemic barriers that impede effective TIC implementation.

#### Step 5: Monitoring and Evaluation

- Create channels for ongoing feedback from staff, especially RSWs, to monitor the effectiveness of TIC implementation and make necessary adjustments.
- Regularly evaluate the impact of TIC on both staff well-being and YPWID outcomes, using qualitative and quantitative measures.

- Based on evaluation results, refine practices, and consider scaling successful strategies across other services and settings.

#### 4.2.3. Implications for Policy

4.2.3.1. *Reducing unnecessary inpatient care and medication of YPWID*: This research has added to a body of literature describing links between traumatic or adverse experience and challenging behaviour in YPWID. Two policy areas have aimed to reduce unnecessary restrictive practices in response to challenging behaviour, through institutionalisation and medication (DoHSC, 2022; Parkin, 2023; NHS, 2019a, 2019b), highlighting the need for increased community capability in understanding and supporting challenging behaviour. In addressing the aims of these policies, the findings of this study support the implementation of TIC throughout services for YPWID, supporting previous research in evidencing the following:

- Identification of trauma and prevention of associated triggers may reduce incidence of challenging behaviour.
- Interpretation of challenging behaviour is a factor in how it is managed and it's impact on supporters. Interpreting behaviour as a response to traumatic or adverse experiences may help staff respond more compassionately and improve staff wellbeing.
- Services should be aware of the impact of challenging behaviour on RSW and seek to support them, to reduce burnout and vicarious trauma and ensure consistent, compassionate care.

4.2.3.2. *Improving support for YPWID in residential care*: The Children's Social Care reform strategy (DfE, 2023), set out proposals to address urgent recommendations, and commenced a review to understand what can be done to ensure disabled children can access the right support. This is pertinent given the findings of the current study, which highlights the following relevant recommendations:

- Health and social care workers should be provided with training to understand the prevalence and impact of trauma in YPWID, with aims of eradicating medicalised ideologies and diagnostic overshadowing.



- Implementation of TIC for YPWID in residential care, including early and thorough assessment of needs with a focus on understanding a broad range of possible adverse experiences and development of care plans based on TIC values.
- Guidelines should be implemented to ensure YPWID enter residential care with clear and comprehensive historical records, identifying potentially adverse or traumatic factors at the social, inter-personal and community level.

The strategy sets out that children and young people in out-of-home care should be provided with stable homes, aiming to improve current homes and develop new provision. The present research emphasises the need for adequately resourced homes for traumatised YPWID and transparency in inter-agency communication to ensure appropriate placement and avoid unnecessary moves, attachment disruptions and re-traumatisation.

*4.2.3.3. Workforce development:* The evidence provided here emphasises the need to stabilise the residential care workforce for YPWID. In response to concerns around staff recruitment and retention (CDC., 2022, 2023), the UK government detailed various routes for workforce development (DoE., 2023). Evidence provided here supports the translation of the following government proposals into policy, noting further recommendations:

- Ongoing research: Whilst focussing on recruitment, retention, qualifications and training, research should consider the prevalence and impact of trauma on YPWID, supporters and services.
- Extend current information-gathering processes: Future census should aim to capture information on residential services for YPWID, to understand the specific needs of this workforce.
- Professional registration for RSW: The systemic de-valuing of RSW in services for YPWID has implications for staff wellbeing, retention, and quality of care. Professional registration would formalise the roles value to society and present it as a career, aiding recruitment and retention. This would allow for the building of knowledge through experienced staff who feel valued, also holding services accountable for delivering training

and supervision and holding RSW accountable to delivering high quality care.

- Increase wages: Wage increases could support the stabilisation and welfare of the RSW workforce, improving wellbeing and assisting in recruitment and retention.

#### 4.2.4. Implications for Research

This study and its limitations provide various evidence for future research. Although this research aimed to speak to staff from a range of residential services for YPWID, no participants worked in residential schools. This may be an area with its own specific challenges and future research could seek to capture the perspective of RSW in these organisations.

As most research focusses on adult populations, further research into the experience of YPWID who have experienced trauma is warranted. Researchers could seek to engage with YPWID directly to understand what they experience as traumatic and their views on how this affects them. They could also seek to understand the views of other stakeholders such as families and school staff.

There has been limited consideration of the interaction of other characteristics such as ethnicity, gender and sexuality on the experiences of PWID who have experienced trauma, none has been found which specifically concerns YPWID. This is particularly relevant as research has shown that people from racialised backgrounds are over-represented amongst ID populations (CDC., 2023), and experience increased rates of oppression and discrimination (Levine & Breshears, 2019; Nazroo et al., 2020). Future research may seek to understand how these factors interact through seeking the views and experiences of YPWID and other key stakeholders and through larger scale quantitative designs.

Whilst frameworks and guidance have been developed for the implementation of TIC in ID services (Goad, 2021; McNally, 2022), these are based on literature concerning adult populations. Future research could build on this study by exploring the views of YPWID to collaboratively develop a framework for TIC in residential services for YPWID.

### **4.3. Critical Evaluation**

This study will be evaluated using a quality assessment framework outlined by Spencer & Ritchie (2011), which highlights principles of Contribution, Credibility and Rigour.

#### **4.3.1. Contribution**

The principle of contribution focuses on how existing knowledge has been expanded by the current study and its potential impact on research, policy, and practice. Previous research has explored the views of RSW on supporting trauma in adult ID settings and in children's residential services, however this research is novel in specifically aiming to gain insight into the views of RSW in services for YPWID. It highlights RSW's specific insight into the causes and presentation of trauma and barriers and facilitators of support in these settings. As described, findings have relevance for clinical practice and policy as well as in the implementation of TIC in residential services for YPWID, serving as a reference for professionals and services working with YPWID who may seek to develop services which better acknowledge and support trauma.

#### **4.3.2. Credibility**

Credibility pertains to the defensibility and plausibility of assertions made in research, encompassing not only the credibility of findings but also understanding how claims or conclusions were derived. The study rationale and aims were considered with relevance to existing literature, to ensure credibility and each stage of the project was developed through consultation with a research supervisor. Each theme in the Results chapter is evidenced with extracts from the data, to illustrate the themes and aid the reader in understanding the conclusions drawn. In terms of bias, a reflective log was kept throughout the research process (Appendix B) and issues related to researcher reflexivity have been described in the Methods and Discussion section.

#### **4.3.3. Rigour**

This focuses on the methodological validity of the research process, involving a thorough, reflective, and well-documented approach to data analysis, the use of suitable methodology, and the exploration of ethical considerations.

The use of semi-structured individual interviews and a flexible interview style which allowed for follow-up questions based on the answers of participants, allowed for the collection of rich, experientially focussed data. The research process has been carefully considered and documented in the Methods section and the research supervisor was consulted at every stage, providing feedback and guidance on coding and theme generation. As described, high levels of attention were paid to the development of themes which reflected the data, through transcription and re-reading and repetition of coding to ensure thorough analysis before themes were addressed. The process of theme development involved engagement with the data both online and on paper, with the development of various thematic maps which allowed for different levels of perspective. The inclusion of reflective log, annotated transcript extract and thematic maps (Appendices; B,K,M) aids transparency of the research process with view to evidencing rigour.

#### **4.4. Limitations**

Various limitations have been considered with relevance to this study. One limitation in study design is the dearth of literature pertaining to this specific population. As discussed, research traditions have compartmentalised ID, trauma and childhood trauma research and whilst many children's residential services serve YPWID, this intersection has not been frequently discussed in the literature. This meant inferences were made from adult ID, child and trauma literature. Whilst this highlights this topic as important for knowledge development, it could be argued that a broader, quantitative approach to evidencing the prevalence and impact of trauma in this specific population may have been an advantageous starting point.

The term 'difficult life experiences' was used within the interview schedule, instead of 'trauma.' While this term was chosen to allow participants to reflect on a wider range of experiences, it may necessitate caution when comparing these

findings with research that specifically uses the term 'trauma'. The term "difficult life experiences" could be seen as more subjective, potentially leading to a wider range of responses, with more diverse themes but which are potentially less focused, consistent and relevant to trauma-focussed outcomes.

In terms of quality assurance, a limitation includes that themes were not fed back to participants for checking and collaboration on use of thematic labels. This bears risk that themes did not fully and accurately represent the participants perspective and could result in a gap between analysis and participants lived experience. Feeding themes back to participants for collaboration would have been advantageous in clarifying meaning which could have helped refine thematic labels and in empowering participants within the research process.

The study sought to include views of participants from a range of residential services, however despite outreach, no staff from residential schools participated. Since these services likely represent a large portion of YPWID in residential care, their input may have enriched the data. Participants worked in diverse settings and reported varying experiences of management, organisational culture, time in their role and number of YPWID they support. Whilst this diversity aimed to reflect the workforce realistically, it was sometimes challenging to generate themes whilst acknowledging nuances in the data. Additionally, the advert's wording likely attracted participants who were invested in the wellbeing and needs of YPWID, and who had some understanding of trauma. Although participants appeared to represent a diverse group, demographic data was not captured, meaning demographic characteristics cannot be discussed with relevance to the results or research validity. Future research in this area should seek to capture this information.

Participants were assured of the steps taken to ensure confidentiality, however, some may have been concerned about being identified by their responses and may not have felt able to give a realistic account of their experiences or views.

Unexpectedly, minimal mention was made of factors specifically pertaining to childhood and adolescence, more specific questions (e.g. around the impact of

sibling relationships, puberty or schooling), may have provided deeper insight into the specific needs of this group.

Many services were contacted with request to circulate the study however the majority refused or did not respond. Understanding the reasons service managers chose not to engage with the research would be useful for the development of future research.

## **4.5. Reflexivity**

### **4.5.1. Personal Reflexivity**

A key point for reflection was the power differences between myself and participants due to my status as a trainee clinical psychologist, and how this may have impacted the design of the study, what they felt comfortable to discuss and my interpretation. I realised early in the design phase that RSW may feel like they are being tested and took effort to ensure clear aims of learning from RSW, not testing them. I aimed to maintain a curious stance throughout the interviews and took steps to make participants feel at ease through humour, warmth and informal conversation, however I was aware the nature of the questions implied a level of ideological power which I held as a Doctoral researcher in clinical psychology. This was evident in some interviews where I noticed participants frequently checked in to see if their answers were correct (see Appendix B), this may have also meant some RSW were hesitant to put forward ideas which might not fit with my professional stance, instead emphasising their lack of training. When I noticed a participant appeared hesitant or was checking my approval of their response, I made effort to emphasise my curiosity about their specific experience and praise their insight and knowledge. I was glad that participants felt able to open-up and reflect on their experiences throughout the interview process and my position as a psychology trainee may have assisted this. However, they could also have understood the type of responses I was looking for and tailored their answers accordingly.

I have reflected on my own cultural background and privilege which may have influenced my study design or interpretation. I neglected to attend to issues of race or intersectionality in the study design and my position as a white trainee may have influenced what participants from racialised backgrounds felt able to discuss.

I have reflected on my personal connection to this research. In the early stages of the design process I acknowledged that I held views about RSW knowledge and practices, based on my personal experiences. These views evolved as I explored the literature, and I took care to ensure they did not alter my interview design. During interviews I acknowledged discomfort around certain topics (e.g. Appendix B) and took care that this did not influence the course of the interview. I did not discuss my personal experience with participants in case it impacted what they chose to discuss.

My personal experience in this area may have influenced the way I interpreted the data, as the views and knowledge I have acquired are rooted in personal and emotive experiences. The keeping of a reflexive journal and discussion with the supervisor aided this process. Furthermore, my experience working with RSW in ID services has been limited to a six-month adult placement, limiting my understanding of service context and meaning I could have overlooked important organisational factors.

#### 4.5.2. Functional and Disciplinary Reflexivity.

My understanding of the impact of trauma and TIC has been developed through a set of professional and personal experiences. Though my research did not aim to analyse responses based on the TIC framework, the questions were designed to fit with TIC principles. This, and my understanding of TIC may have affected data interpretation. For example, I may have conceptualised a subject as 'resistance to re-traumatisation', even if this was not the way it was meant, because of my knowledge of this term, meaning my findings could have been influenced by my training and epistemological position.

Throughout the research process I aimed to maintain alignment with qualitative values and acknowledge and counter my positivist thinking. Despite finding the

uncertainty in this approach challenging at times, I committed to these values through focussing on meaning and nuance, maintaining curiosity, reflecting on dominant cultural assumptions, and accepting that the knowledge generated in this study comes from a position and does not represent a singular truth.

#### **4.6. Conclusion**

This is the first known study to explore RSW insight into supporting YPWID who have experienced trauma. This is an important area for research based on the prevalence of trauma in YPWID and historical, ideological barriers which have prevented it's acknowledgement in clinical practice and research. It has relevance to UK policy aimed at improving support for YPWID with challenging behaviour, safeguarding disabled children, and reforming support for children in residential care. This research is particularly important in the context of health and wellbeing disparities in PWID and the knowledge that early intervention in childhood is advantageous for improving outcomes (Marmot et al., 2008, 2020; World Health Organisation, 2014, 2018).

Findings highlighted that, despite initial difficulties conceptualising trauma, RSW implied a broad knowledge of causes and impact of trauma in YPWID which corresponds to the evidence base. Findings highlighted that trauma training would be advantageous in developing an understanding of trauma which extends beyond abuse, and consideration of the impact of trauma on health. Evidence suggests that trauma-focussed training would be well received and understood by RSW in this context. The study highlights the complex processes RSW engage in to resist the barriers imposed by a dysfunctional system and seek to make reparations within the young people's lives, through the support they provide. Findings suggest that an emphasis on relational safety as a method of support and reparation is particularly relevant to this population.

This research highlighted various systemic barriers to support, involving the marginalisation of YPWID in communities, abandonment by services, organisational level factors such as poor staffing, training and resource and the emotional impact of the work on RSW. Finally, participants viewed their role as



more than a job, as a vocation, based on a sense of personal duty, acknowledging that they are skilled workers with expertise and should be valued by their organisations, professionals and society.

Implications demonstrate the need for systemic change and potential avenues in which this could take place. Including organisational strategies which prioritise RSW wellbeing through ensuring their safety and demonstrating their values. Findings emphasise the place of TIC in enhancing support for YPWID, improving the working environment of RSW and increasing capability of community services. At the policy level, implications include an urge for policy interventions to promote the implementation of TIC and focus on RSW workforce development. Future research should expand the focus on diverse experiences within this population and develop a framework for TIC in child ID residential services, ultimately advancing the quality of care and support for YPWID who have experienced trauma.

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## APPENDIX A: Exclusion Criteria and Search Strategy

### Exclusion Criteria

- Not relevant to at least 3 subject terms (Appendix A)
- Studies focussed on staff wellbeing.
- Studies focussed on implementation or assessment of trauma interventions.
- Studies focussed on understanding prevalence of trauma/ACEs
- Studies focussed on experience of family carers
- Studies which do not include staff perspective
- Unpublished thesis, meta-analysis, policy

### Search terms

	Subject 1	Subject 2	Subject 3	Subject 4	Subject 5
<b>Key terms</b>	Young People	Intellectual Disability	Trauma	Staff	Residential Care
<b>Alternatives</b>	Children	Learning Disability	Emotional Trauma	Residential Support Workers	Supported living
	Adolescents	Mental Handicaps	Adverse childhood experiences	Direct Care Workers	Children's home
	Young Adults	Mental Retardation	Childhood adversity	Support workers	Child residential services
		Mental disability	Abuse	Residential staff	
		Developmental disability	Neglect	Residential workers	
		Downs Syndrome	PTSD	Healthcare staff	
		Prader-Willi syndrome	Complex trauma	Professionals	
		Special educational needs		Practitioners	
		Neurodevelopmental disorders		Clinicians	
		Developmental delay		Care Staff	

				Support Staff	
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Final search strategy:

	Subject	Subject	Subject
Search 1	Young People	ID	Trauma
Search 2	Young People	ID	RSW
Search 3	Young People	ID	Residential Care
Search 4	Young People	Trauma	RSW
Search 5	Young People	Trauma	Residential Care
Search 6	Young People	RSW	Residential Care
Search 7	ID	Trauma	RSW
Search 8	ID	Trauma	Residential Care
Search 9	ID	RSW	Residential Care

E.g. Search 1:

("Young People" OR "Children" OR "Adolescents" OR "Young Adults) AND ("Intellectual Disability" OR "Learning Disability" OR "Mental Handicap" OR "Mental Retardation", "Mental disability" OR "Developmental disability" OR "Downs Syndrome" OR "Prader-Willi syndrome" OR "Special educational needs" OR "Neurodevelopmental disorders" OR "Developmental delay") AND ("Trauma" OR "Emotional Trauma" OR "Adverse childhood experiences" OR "Childhood adversity" OR "Abuse" OR "Neglect" OR "PTSD" OR "Complex trauma")

## **APPENDIX B: Reflexive Journal Extract**

23/08/23

I felt nervous before my first interview today, I worked to control my nerves so I could ensure my questions were succinct and I could attend to the participants responses. This interview raised some personal challenges as the participant discussed the family of a YP they support with disdain due to their lack of involvement with their child. I realised this was bringing up feelings due to my position as a family member and worked to remain curious but committed to the focus of the interview, rather than become defensive of the family or diverted by my personal feelings around this issue. Following the interview, I have acknowledged feelings of frustration and guilt arising as a result of these comments. I am aware I need to be prepared for similar perspectives throughout the interview process and ensure I am not distracted by them so I can fully attend to the participant.

29/09/23

During today's interview, I encountered a challenging moment as the participant found it quite difficult to describe the impact of trauma and I needed to provide a few prompts. They sought validation a few times, asking if what they said was right. This encounter sparked a deeper reflection on the power dynamics between us. I realised that my position of perceived authority could inadvertently create a barrier for participants, possibly leading them to withhold insights or express uncertainties. I am aware of the delicate balance required to foster a supportive environment where participants can openly share without feeling judged or inadequate. Moving forward, I am committed to refining my approach to empower participants and elicit more nuanced and authentic reflections.

12/10/23

I'm questioning whether my discomfort during certain interview moments has impacted the quality of responses received. Navigating power dynamics sensitively while ensuring participants feel valued has been a challenge at times, I wonder if my desire to make participants feel comfortable and not scrutinised has led me to avoid pushing them for clearer answers. I feel a lot of them imply a good understanding, but I'm wondering if the data reflects this? I am committed to refining my approach to elicit more authentic and nuanced reflections from participants.

## **APPENDIX C: Study Advert**



## SUPPORTING YOUNG PEOPLE WITH LEARNING DISABILITIES WHO HAVE EXPERIENCED CHALLENGING LIFE EVENTS



Are you a support worker or carer for young people with Learning Disabilities aged 12-25 in a residential service?

If so we are interested in talking with you.

## WE WANT TO LEARN FROM SUPPORT WORKERS



We are conducting research to understand how services can better support young people with learning disabilities who have experienced challenging or traumatic life events.

Interviews will take place online for 40-60minutes.  
You will receive a £10 Amazon voucher for participation



For more information or to take part contact  
Merry Wright, Trainee Clinical Psychologist

email: [U2075235@Uel.ac.uk](mailto:U2075235@Uel.ac.uk)

Ethical approval gained through the University of East London



## **PARTICIPANT INFORMATION SHEET**

Date: 15/06/2023

Version: 1

### **Exploring residential support workers insight into supporting young people with learning disabilities who have experienced trauma.**

**Contact person:** Merry Wright

**Email:** U2075235@UEL.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

#### **Who am I?**

My name is Merry. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and am studying for a Doctorate in Clinical Psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

#### **What is the purpose of the research?**

I am conducting research to help understand the best ways of supporting young people with learning disabilities who have been through challenging life events and trauma.

We know that previous challenging and traumatic life events can be linked to problems with mental health in all people, however only recently researchers have started to look at how people with learning disabilities might be affected. Links have been found between traumatic experiences and challenging behaviour in people with learning disabilities. Some organisations are now starting to introduce 'trauma informed care' as a way of supporting their clients.

Support workers make up a key part of the community around people with learning disabilities and so will have a unique insight into how these young people are impacted by trauma in their daily lives, alongside understanding of how services can best support them or how things could be done differently.

My aim is to explore support workers views and experiences to think about ways services might be able to support these young people in the best way possible. In the long term this could help with the design of new ways of working in services which consider the needs of both service users and support staff.

### **Why have I been invited to take part?**

To address the study aims, I am inviting residential support workers/care staff to take part in my research. If you are a residential support worker or carer, are over 18 and can understand and speak English well enough to take part in an interview, then you are eligible to take part in the study.

It is entirely up to you whether you take part or not, participation is voluntary.

### **What will I be asked to do if I agree to take part?**

If you agree to take part, you will be asked to take part in an interview, which will be like an informal chat about your views and experiences.

- You will be asked to consent to take part in the study using an online form
- We will arrange a interview at a convenient time for you
- Interviews will take place on Microsoft Teams, but you will not be required to have your camera on if you don't want to.
- Interviews will take between 40-60minutes
- The interview will be recorded using Microsoft teams
- You will receive a £10 Amazon voucher for taking part.

### **Can I change my mind?**

Yes, you can change your mind at any time and withdraw without explanation, disadvantage or consequence.

- If you would like to withdraw from the interview before it has taken place you can let me know via email
- If the interview has already started you can ask for it to be stopped at any time.

Separately, you can also request to withdraw your data from being used even after you have taken part in the study, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

### **Are there any disadvantages to taking part?**

- You won't be asked to talk about your personal life experiences, however sometimes thinking about challenges that others have been through can make us think about our own struggles and this might bring up some difficult thoughts and feelings.
- Additionally, the discussion might lead you to talk about times you have worked with challenging behaviour which may also bring up difficult thoughts and feelings.
- If you feel upset or distressed at any time during the interview you can ask for it to be paused or stopped
- If you don't want to answer a question you can let me know and we will move on
- I will offer to arrange a debrief call the week after your interview so you can discuss any thoughts or feelings that came up for you during the interview or afterwards.
- I will also provide a debrief form which will have details of support services you can contact

### **How will the information I provide be kept secure and confidential?**

*Confidentiality is an important issue for this project. In compliance with GDPR principles and the Data protection act:*

- Participants will not be identified by the data collected, on any material resulting from the data collected, or in any write-up of the research. We will make sure of this in the following ways:
  - All data will be saved on the lead researchers UEL OneDrive for business account, accessible only to the lead researcher through a password protected account using Multi-Factor authentication.
  - When you agree to take part in the research you will be allocated a participant number.
  - The participant number will be saved next to your email address in a password protected spreadsheet accessible only to the lead researcher on the researchers private OneDrive account protected using multi-factor authentication
  - All other information related to you will be identifiable only by the participant number, this is so if you decide you want to withdraw from the study we will know which data to delete.
  - After the interview takes place it will be transcribed by the lead researcher. The original recording will then be deleted
  - When transcribing the interview all identifying information related to you, your service and your clients will be removed
- Data will only be used for the purposes it was obtained and will not be retained longer than necessary (recordings will be deleted following transcription, other information will be kept only for the duration of the project)
- The minimum amount of personal information will be collected.
- Anonymised transcripts and analysis will be shared only with the research supervisor through UEL OneDrive for Business



- The final write up of the project will include some quotes from the interviews. These will be fully anonymised and all identifiable information will have been removed.
- After the project is complete the log which contains data to identify participants and any other participant information will be deleted. No personal details will be saved.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see [www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection](http://www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection)

### **What will happen to the results of the research?**

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository (Registry of Open Access Repositories, ROAR). Findings will also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks, magazine articles, blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally as all identifying information will be removed.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by Dr. Paula Corredor Lopez (Research supervisor) for a maximum of 3 years, following which all data will be deleted.

### **Who has reviewed the research?**

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

### **Who can I contact if I have any questions/concerns?**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me. My details are: Merry Wright,  
Email: U2075235@UEL.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor School of Psychology,  
University of East London, Water Lane, London E15 4LZ,  
Email: P.Corredor-lopez@uel.ac.uk

**or**

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology,  
University of East London, Water Lane, London E15 4LZ.  
(Email: t.patel@uel.ac.uk)

**Thank you for taking the time to read this information sheet**

## APPENDIX E: Consent Form



### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

**Exploring residential support workers insight into supporting young people with learning disabilities who have experienced trauma.**

**Contact person:** Merry Wright

**Email:** U2075235@UEL.ac.uk

	<b>Please initial</b>
I confirm that I have read the participant information sheet dated 09/05/2022 (version 1) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview withdraw my data from the study.	
I understand that the interview will be recorded using Microsoft Teams	
I understand that my personal information and data, including audio/video recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant's Name (BLOCK CAPITALS)

.....  
.....

Participant's Signature

.....  
.....

Researcher's Name (BLOCK CAPITALS)

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Researcher's Signature

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Date

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## APPENDIX F: Ethics Application



University of  
East London

UNIVERSITY OF EAST  
School of Psychology  
Neil Rees

LONDON

APPLICATION FOR RESEARCH ETHICS APPROVAL  
FOR RESEARCH INVOLVING HUMAN PARTICIPANTS  
(Updated October 2021)

FOR BSc RESEARCH;  
MSc/MA RESEARCH;  
PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING &  
EDUCATIONAL PSYCHOLOGY

### Section 1 – Guidance on Completing the Application Form (please read carefully)

1.1	Before completing this application, please familiarise yourself with: British Psychological Society's Code of Ethics and Conduct UEL's Code of Practice for Research Ethics UEL's Research Data Management Policy UEL's Data Backup Policy
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will look over your application and provide feedback.
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for review.
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection must NOT commence until your ethics application has been approved, along with other approvals that may be necessary (see section 7).
1.5	Research in the NHS: If your research involves patients or service users of the NHS, their relatives or carers, as well as those in receipt of services provided under contract to the NHS, you will need to apply for HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of Psychology for ethical clearance. Useful websites: <a href="https://www.myresearchproject.org.uk/Signin.aspx">https://www.myresearchproject.org.uk/Signin.aspx</a> <a href="https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/">https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/</a> If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&D approval. This is in addition to separate approval via the R&D department of the NHS Trust involved in the research. UEL ethical approval will also be required. HRA/R&D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research

	<p>without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example.</p> <p>The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.</p>
1.6	<p>If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to <a href="mailto:applicantchecks@uel.ac.uk">applicantchecks@uel.ac.uk</a>. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website:</p> <p><a href="https://fadv.onlinedisclosures.co.uk/Authentication/Login">https://fadv.onlinedisclosures.co.uk/Authentication/Login</a></p> <p>You may also find the following website to be a useful resource:</p> <p><a href="https://www.gov.uk/government/organisations/disclosure-and-barring-service">https://www.gov.uk/government/organisations/disclosure-and-barring-service</a></p>
1.7	<p>Checklist, the following attachments should be included if appropriate:</p> <p>Study advertisement</p> <p>Participant Information Sheet (PIS)</p> <p>Participant Consent Form</p> <p>Participant Debrief Sheet</p> <p>Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5)</p> <p>Permission from an external organisation (see section 7)</p> <p>Original and/or pre-existing questionnaire(s) and test(s) you intend to use</p> <p>Interview guide for qualitative studies</p> <p>Visual material(s) you intend showing participants</p>

## Section 2 – Your Details

2.1	Your name:	Merry Wright
2.2	Your supervisor's name:	Dr. Paula Corredor-Lopez
2.3	Name(s) of additional UEL supervisors:	Dr. Trishna Patel 3rd supervisor (if applicable)
2.4	Title of your programme:	Professional Doctorate in Clinical Psychology
2.5	UEL assignment submission date:	Initial submission date Re-sit date (if applicable)

## Section 3 – Project Details

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.

3.1	<p>Study title:</p> <p><u>Please note</u> - If your study requires registration, the title inserted here must be <u>the same</u> as that on PhD Manager</p>	Exploring residential support workers insight into supporting young people with learning disabilities who have experienced trauma.
3.2	Summary of study background and aims (using lay language):	The effect of trauma and adverse childhood experience on physical and psychological health is widely acknowledged (Norman et al, 2012, Hughes et al, 2017, Reeves, 2015), however the acknowledgement of

		<p>the impact of trauma on people with learning disabilities (LD) has been historically omitted from trauma research, clinical practice and policy (Morris, 2021). The governments 'Transforming care' agenda aims to reduce unnecessary inpatient stays for people with LD (NHS England, 2015) but there is a consensus that more needs to be done to develop community capability so community services can better support people with LD when in distress (Health and Social Care Committee, 2021). Links have been found between traumatic experiences and challenging and offending behaviour in people with LD making trauma a pertinent area for research (Rittmannsberger et al., 2020). Support workers (SW) make up a key part of the community around people with LD (Hastings, 2010). With aims of better understanding how to upskill community services in trauma informed practice, this research will recruit support workers via their organisations and through social media, to take part in semi-structured interviews. Data gathered will be analysed using a reflexive thematic analysis approach framed by a post structural inspired critical disability lens, generating themes to gain insight into support workers knowledge and perspectives</p>
3.3	Research question(s):	<p>What do SW understand about how traumatic or adverse life experiences can impact young people with LD?  How do SW think they can best support young people with LD who have experiences traumatic or adverse life experiences?  How does this fit within current service context?  What is SW experience of supporting young people with LD who have experienced trauma?  How can SW insight be used to assist residential services in integrating trauma informed practice?</p>
3.4	Research design:	<p>This study will utilise a qualitative approach to gain a deeper and nuanced understanding of SW insight. This approach acknowledges that the language that SW use may vary from professional and academic discourse around trauma and allows for rich exploration of their knowledge and perspectives. Individual semi-structured interviews will be conducted, and data will be analysed using a thematic analysis approach to highlight</p>

		personal perspectives and capture narratives which may fall outside current academic discourse.
3.5	<p><b>Participants:</b> Include all relevant information including inclusion and exclusion criteria</p>	<p>8-12 SW will be recruited from private and third sector residential care services either via their organisation or via social media forums SW may be likely to frequent. Participation will be voluntary.</p> <p><b>Inclusion criteria:</b> Must be employed as a support worker in a residential service with young people (under 25) with a diagnosis of LD. Must be able to understand and speak English. Must be age 18+.</p>
3.6	<p><b>Recruitment strategy:</b> Provide as much detail as possible and include a backup plan if relevant</p>	<p>Participants will be recruited one of two ways: Third and private sector residential care services will be approached with information about the study's aims and the request to circulate advertising materials amongst their staff. Advertising materials will be posted in social media forums which SW are likely to frequent.</p>
3.7	<p><b>Measures, materials or equipment:</b> Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.</p>	<p><i>Measures</i> A semi-structured interview format will be utilised. Data will be analysed using a reflexive thematic analysis approach.</p> <p><i>Materials/ equipment:</i> Access to Qualtrics required for sign up and consent form Access to UEL secure data storage. Microsoft Teams downloaded on the researcher's personal laptop. Alternatively, interviews may be conducted over the phone and will be recorded using a Dictaphone.</p>
3.8	<p><b>Data collection:</b> Provide information on how data will be collected from the point of consent to debrief</p>	<p>Consent and demographic information will be collected online via a Qualtrics form (licenced by UEL School of Psychology). Within Qualtrics, the 'anonymise responses' setting will be enabled to ensure data are gathered using anonymous links, removing IP addresses and location data from the results. Participants will indicate consent by ticking a list of statements for various aspects of data collection, storage and use, prior to commencing the study. Data will be downloaded from the Qualtrics server onto an Excel spreadsheet which will be saved</p>



		<p>on the researchers UEL OneDrive for business.</p> <p>Interviews will be conducted via MS Teams installed on the researcher's personal laptop.</p> <p>Files will be automatically saved on the UEL Microsoft Stream Library.</p> <p>Participants will not be required to have their camera on.</p> <p>Interview recordings will be deleted as soon as transcription has taken place.</p> <p>Interview recordings will be automatically transcribed by Microsoft Teams. These will be reviewed by the researcher, checked for accuracy and saved on the researchers UEL OneDrive for business. All identifiable information pertaining to interviewees, their organisation and their clients will be removed from the transcription.</p> <p>A follow up debrief call will be offered at the end of every interview. A debrief form will also be provided via email.</p>	
3.9	Will you be engaging in deception?	YES <input type="checkbox"/>	NO <input checked="" type="checkbox"/>
	If yes, what will participants be told about the nature of the research, and how/when will you inform them about its real nature?		
3.10	Will participants be reimbursed?	YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>
	If yes, please detail why it is necessary.	Support workers often work long hours and are on a low pay scale. They will be required to give up their free time to discuss issues related to their work and it is important they are remunerated for this appropriately.	
	How much will you offer? <u>Please note</u> - This must be in the form of vouchers, <u>not cash</u> .	£10 Amazon voucher per participant	
3.11	Data analysis:	Interview data will be transcribed. Transcriptions will be analysed using a reflexive thematic analysis approach framed by a post structural-inspired critical disability lens to generate themes	

#### Section 4 – Confidentiality, Security and Data Retention

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

If a Research Data Management Plan (RDMP) has been completed and reviewed, information from this document can be inserted here.

4.1	Will the participants be anonymised at source?  If yes, please provide details of how the data will be anonymised.	YES <input type="checkbox"/>	NO <input checked="" type="checkbox"/>
4.2	Are participants' responses anonymised or are an anonymised sample?  If yes, please provide details of how data will be anonymised (e.g., all identifying information will be removed during transcription, pseudonyms used, etc.).	YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>  Participants will register interest in participation via email to the lead researchers UEL email address. From here their email address will be recorded into a spreadsheet alongside a participant number and their original email will be deleted. A separate spreadsheet will contain a record of consent and basic demographic information alongside the corresponding participant number Video interviews will be transcribed and all identifying information, including that pertaining to the participant, their organisation and thier clients, will be removed Video interviews will be deleted following transcription Pseudonyms will be used in write up and dissemination
4.3	How will you ensure participant details will be kept confidential?	In line with GDPR and the Data Protection Act, all data (including sensitive and pseudonymised) will be saved on the lead researchers UEL OneDrive for business account, accessible only to the lead researcher through a password protected account using Multi-Factor authentication. Personal data will not be stored longer than necessary (recordings will be deleted following transcription, other information will be kept only for the duration of the project) The minimum amount of personal information will be collected. The majority of the data will be pseudonymised transcriptions. This data will be saved alongside a participant number so it can be identified if necessary (eg. if the participant requests to withdraw their data).	
4.4	How will data be securely stored and backed up during the research? Please include details of how you will manage access, sharing and security	All data will be stored on the UEL Microsoft OneDrive for business aside from MS teams video recordings which will be stored by default on the UEL Microsoft Stream Library. Recordings and will be deleted as soon as they have been transcribed and checked for accuracy. Total data size is not expected to exceed the UEL personal OneDrive allowance.	

		The researchers UEL OneDrive for business will contain a 'Thesis' folder, divided into two separate folders to separate pseudonymised data from identifiable data: A folder titled 'Sensitive Data' will contain Spreadsheet 1 and 2, containing identifiable information including contact information and basic demographic information. A folder titled 'Project' will contain pseudonymised data including interview transcripts, analysis and project write up.	
4.5	Who will have access to the data and in what form? (e.g., raw data, anonymised data)	The lead researcher will have sole access to identifiable data Pseudonymised data (eg. transcripts and analysis in .doc format) will be shared only with the research supervisor through UEL OneDrive for Business	
4.6	Which data are of long-term value and will be retained? (e.g., anonymised interview transcripts, anonymised databases)	Pseudonymised data (eg. transcripts and analysis) will be stored for three years for dissemination purposes	
4.7	What is the long-term retention plan for this data?	Data of long-term value will be shared with the research supervisor through UEL OneDrive for Business. The final project write up will be shared through UEL's research repository.	
4.8	Will anonymised data be made available for use in future research by other researchers?	YES <input type="checkbox"/>	NO <input checked="" type="checkbox"/>
	If yes, have participants been informed of this?	YES <input type="checkbox"/>	NO <input type="checkbox"/>
4.9	Will personal contact details be retained to contact participants in the future for other research studies?	YES <input type="checkbox"/>	NO <input checked="" type="checkbox"/>
	If yes, have participants been informed of this?	YES <input type="checkbox"/>	NO <input type="checkbox"/>

## Section 5 – Risk Assessment

If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g., a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

5.1	Are there any potential physical or psychological risks to participants related to taking part? (e.g., potential adverse effects, pain, discomfort, emotional distress, intrusion, etc.)	YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>
	If yes, what are these, and how will they be minimised?	Although participants will not be asked to talk about their personal lives, it is recognised	

		that discussion of the subject of trauma may bring up difficult emotions for participants. Additionally, questions may lead them to reflect on experiences of managing or witnessing high levels of distress in the individuals they support and/or behaviour that challenges which may be linked to vicarious trauma.		
5.2	Are there any potential physical or psychological risks to you as a researcher?	YES <input type="checkbox"/>	NO <input checked="" type="checkbox"/>	
	If yes, what are these, and how will they be minimised?			
5.3	If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that you have attached a GRA form as an appendix:	YES <input checked="" type="checkbox"/>		
5.4	If necessary, have appropriate support services been identified in material provided to participants?	YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>	N/A <input type="checkbox"/>
5.5	Does the research take place outside the UEL campus?	YES <input checked="" type="checkbox"/>		NO <input type="checkbox"/>
	If yes, where?	Interviews will take place remotely via MS Teams		
5.6	Does the research take place outside the UK?	YES <input type="checkbox"/>		NO <input checked="" type="checkbox"/>
	If yes, where?			
	If yes, in addition to the General Risk Assessment form, a Country-Specific Risk Assessment form must also be completed and included (available in the Ethics folder in the Psychology Noticeboard). Please confirm a Country-Specific Risk Assessment form has been attached as an appendix. <u>Please note</u> - A Country-Specific Risk Assessment form is not needed if the research is online only (e.g., Qualtrics survey), regardless of the location of the researcher or the participants.	YES <input type="checkbox"/>		
5.7	Additional guidance: For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then			

'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance.

For on campus students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Director of Impact and Innovation, Professor Ian Tucker (who may escalate it up to the Vice Chancellor).

For distance learning students conducting research abroad in the country where they currently reside, a risk assessment must also be carried out. To minimise risk, it is recommended that such students only conduct data collection online. If the project is deemed low risk, then it is not necessary for the risk assessment to be signed by the Director of Impact and Innovation. However, if not deemed low risk, it must be signed by the Director of Impact and Innovation (or potentially the Vice Chancellor).

Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

Section 6 – Disclosure and Barring Service (DBS) Clearance			
6.1	Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)? If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project	YES <input type="checkbox"/>	NO <input checked="" type="checkbox"/>
<p>* You are required to have DBS or equivalent clearance if your participant group involves:</p> <p>(1) Children and young people who are 16 years of age or under, or</p> <p>(2) 'Vulnerable' people aged 16 and over with particular psychiatric diagnoses, cognitive difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak with your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible.</p>			
6.2	Do you have DBS or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project?	YES <input type="checkbox"/>	NO <input checked="" type="checkbox"/>
6.3	Is your DBS or equivalent (for those residing in countries outside of the UK) clearance valid for the duration of the research project?	YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>

6.4	If you have current DBS clearance, please provide your DBS certificate number:	001779332576
	If residing outside of the UK, please detail the type of clearance and/or provide certificate number.	
6.5	<p>Additional guidance:          If participants are aged 16 or under, you will need two separate information sheets, consent forms, and debrief forms (one for the participant, and one for their parent/guardian).          For younger participants, their information sheets, consent form, and debrief form need to be written in age-appropriate language.</p>	

### Section 7 – Other Permissions

7.1	Does the research involve other organisations (e.g., a school, charity, workplace, local authority, care home, etc.)?	YES <input type="checkbox"/>	NO <input checked="" type="checkbox"/>
	If yes, please provide their details.		
	If yes, written permission is needed from such organisations (i.e., if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation). Please confirm that you have attached written permission as an appendix.	YES <input type="checkbox"/>	
7.2	<p><u>Additional guidance:</u>          Before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application or approval letter. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as ‘my’ or ‘I’ with ‘our organisation’ or with the title of the organisation. This organisational consent form must be signed before the research can commence.          If the organisation has their own ethics committee and review process, a SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s.</p>		

### Section 8 – Declarations

8.1	Declaration by student. I confirm that I have discussed	YES <input checked="" type="checkbox"/>
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	the ethics and feasibility of this research proposal with my supervisor:	
8.2	Student's name: (Typed name acts as a signature)	Merry Wright
8.3	Student's number:	2075235
8.4	Date:	13/05/2022
<i>Supervisor's declaration of support is given upon their electronic submission of the application</i>		

## APPENDIX G: Ethical Approval Letter



University of  
East London

### School of Psychology Ethics Committee

## NOTICE OF ETHICS REVIEW DECISION LETTER

**For research involving human participants**

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational  
Psychology

**Reviewer:** Please complete sections in **blue** | **Student:** Please complete/read sections  
in **orange**

Details	
<b>Reviewer:</b>	Please type your full name <b>Lucia Berdondini</b>
<b>Supervisor:</b>	Please type supervisor's full name <b>Paula Corredor Lopez</b>
<b>Student:</b>	Please type student's full name <b>Merry Wright</b>
<b>Course:</b>	Please type course name <b>Prof Doc in Educational and Child Psychology</b>
<b>Title of proposed study:</b>	<b>Exploring residential support workers insight into supporting young people with learning disabilities who have experienced trauma.</b>

Checklist (Optional)			
	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Detailed account of participants, including inclusion and exclusion criteria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding participants/target sample	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Detailed account of recruitment strategy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding recruitment strategy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clear and detailed outline of data collection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Data collection appropriate for target sample	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding data storage (e.g., location, type of data, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding data sharing (e.g., who will have access and how)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, General Risk Assessment form attached	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, Country-Specific Risk Assessment form attached	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, a DBS or equivalent certificate number/information provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All relevant information included in the participant information sheet (PIS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information in the PIS is study specific	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language used in the PIS is appropriate for the target audience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All issues specific to the study are covered in the consent form	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language used in the consent form is appropriate for the target audience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All necessary information included in the participant debrief sheet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language used in the debrief sheet is appropriate for the target audience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Study advertisement included	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Decision options	
<b>APPROVED</b>	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
<b>APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED</b>	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made <b>before</b> the research commences. Students are to do this by filling in the confirmation box

<p><b>BEFORE THE RESEARCH COMMENCES</b></p>	<p>at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records.</p> <p><b>Minor amendments guidance:</b> typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.</p>
<p><b>NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED</b></p>	<p>In this circumstance, a revised ethics application <b>must</b> be submitted and approved <b>before</b> any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.</p> <p><b>Major amendments guidance:</b> typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.</p>

Decision on the above-named proposed research study

<p>Please indicate the decision:</p>	<p><b>APPROVED</b></p>
--------------------------------------	------------------------

Minor amendments

Please clearly detail the amendments the student is required to make

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher		
Has an adequate risk assessment been offered in the application form?	<b>YES</b> <input checked="" type="checkbox"/>	<b>NO</b> <input type="checkbox"/>
	If no, please request resubmission with an <b><u>adequate risk assessment.</u></b>	
If the proposed research could expose the <b>researcher</b> to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
<b>HIGH</b>	Please <b>do not approve a high-risk</b> application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	<input type="checkbox"/>
<b>MEDIUM</b>	Approve but include appropriate recommendations in the below box.	<input type="checkbox"/>
<b>LOW</b>	Approve and if necessary, include any recommendations in the below box.	<input checked="" type="checkbox"/>
<b>Reviewer recommendations in relation to risk (if any):</b>	Please insert any recommendations	

Reviewer's signature	
<b>Reviewer:</b> (Typed name to act as signature)	<b>Lucia Berdondini</b>
<b>Date:</b>	<b>14/06/2023</b>
<b><i>This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee</i></b>	

**RESEARCHER PLEASE NOTE**  
 For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

**Confirmation of minor amendments  
(Student to complete)**

**I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data**

<b>Student name:</b> (Typed name to act as signature)	Please type your full name
<b>Student number:</b>	Please type your student number
<b>Date:</b>	Click or tap to enter a date

***Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required***

## UEL Data Management Plan

Completed plans **must** be sent to [researchdata@uel.ac.uk](mailto:researchdata@uel.ac.uk) for review

*If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).*

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

<b>Administrative Data</b>	
PI/Researcher	<b>MERRY WRIGHT</b>
PI/Researcher ID (e.g. ORCID)	2075235
PI/Researcher email	U2075235@UEL.AC.UK
Research Title	<b>Exploring residential support workers insight into supporting young people with learning disabilities who have experienced trauma.</b>
Project ID	
Research start date and duration	
Research Description	<p>The proposed research aims to fill a gap in the literature by exploring residential support workers insight into the impact of trauma on young people with learning disabilities whom they support, alongside perspectives on how services can effectively support this client group.</p> <p>The effect of trauma and adverse childhood experience on physical and psychological health is widely acknowledged, however the acknowledgement of the impact of trauma on people with learning disabilities has been historically omitted from trauma research,</p>

	<p>clinical practice and policy. Support workers make up a key part of the community around people with learning disabilities and may have unique insight and understanding into how this population are impacted by trauma, alongside ways in which services might better support them.</p> <p>With aims of better understanding how to upskill community services in trauma informed practices, this research will recruit support workers via their organisations and through social media, to take part in semi-structured interviews. Data gathered will be analysed using a reflexive thematic analysis approach framed by a post structural inspired critical disability lens, generating themes to gain insight into support workers knowledge and perspectives.</p>
Funder	N/A – Part of professional doctorate
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	20/04/2022
Date of last update (of DMP)	
Related Policies	<p>UEL Research Data Management Policy</p> <p>UEL Data Backup Policy</p> <p>UEL Statement on Research Integrity</p> <p>UEL Statement on Research Ethics</p> <p>The Data Protection Act</p>
Does this research follow on from previous research? If so, provide details	N/A
<b>Data Collection</b>	
What data will you collect or create?	<ul style="list-style-type: none"> <li>• Spreadsheet 1: including contact information for participants and assigned participant numbers in .xls format. Contains personal data.</li> <li>• Spreadsheet 2: Indication of consent and basic demographic information (service type and job role but no name, address or contact information) will be saved in .xls format alongside corresponding participant number. Contains some personal data.</li> </ul>

	<ul style="list-style-type: none"> <li>• Video interview recordings: .mp4 format (8-12 files, approx. 4.8GB total). May contain personal data.</li> <li>• Pseudonymised written transcripts in .doc format</li> <li>• Documents in .doc format pertaining to the analysis and write up of the data.</li> </ul>
<p>How will the data be collected or created?</p>	<ul style="list-style-type: none"> <li>• Participants will register interest in participation via email to the lead researchers UEL email address. From here their email address will be recorded into a spreadsheet alongside a participant number and their original email will be deleted.</li> <li>• Consent and demographic information will be collected online via a Qualtrics form (licenced by UEL School of Psychology). Within Qualtrics, the 'anonymise responses' setting will be enabled to ensure data are gathered using anonymous links, removing IP addresses and location data from the results. Participants will indicate consent by ticking a list of statements for various aspects of data collection, storage and use, prior to commencing the study. Data will be downloaded from the Qualtrics server onto an Excel spreadsheet which will be saved on the researchers UEL OneDrive for business.</li> <li>• Interviews will be conducted via MS Teams installed on the researcher's personal laptop. <ul style="list-style-type: none"> <li>○ An interview schedule will be developed so a standard format is followed</li> <li>○ Interview recordings will be automatically saved on the UEL One Drive of the lead researcher conducting the interview</li> <li>○ Participants will not be required to have their camera on.</li> <li>○ Recordings will be stored following the file-naming convention: <b>[ProjectCode]-[InterviewerInitials]-[ParticipantNumber]-[Location]-[Date].Ext</b></li> <li>○ Interview recordings will be deleted as soon as transcription has taken place.</li> </ul> </li> <li>• Interview recordings will be manually transcribed by the researcher onto a word document which will be saved on the researchers UEL OneDrive for business. All identifiable information pertaining to interviewees, their organisation and their clients will be removed from the transcription. <ul style="list-style-type: none"> <li>○ Pseudoanonymised transcripts will be saved separately from the log containing</li> </ul> </li> </ul>

	<p>data which will be used to re-identify participants as necessary (see 'storage and back-up' section)</p> <p>4.6.1.1.</p>
<b>Documentation and Metadata</b>	
<p>What documentation and metadata will accompany the data?</p>	<ul style="list-style-type: none"> <li>• Recruitment poster</li> <li>• Template participant information sheets</li> <li>• Template Consent form</li> <li>• Debrief forms</li> <li>• Interview schedule.</li> <li>• Anonymisation log</li> <li>• Recordings will be stored following the file-naming convention: <b>[ProjectCode]-[InterviewerInitials]-[ParticipantNumber]-[MSTeams]-[Date].Ext</b></li> <li>• Transcripts will be stored following the file-naming convention: <b>[ProjectCode]-[InterviewerInitials]-[ParticipantNumber]-[Trancript]-[Date].Ext</b></li> </ul>
<b>Ethics and Intellectual Property</b>	
<p>Identify any ethical issues and how these will be managed</p>	<p>Ethics approval will be sought from the University of East London (UEL) School of Psychology Research Ethics Committee (SREC).</p> <p><b>Consent</b></p> <ul style="list-style-type: none"> <li>• Prior to sign up participants will be presented with an information sheet outlining requirements, GDPR and confidentiality procedures. Participants will be asked to confirm they have read and understood this information and consent to participation electronically using a Qualtrics form.</li> <li>• At the beginning of the interview participants will again be asked to confirm verbal consent. Participants will be reminded that they have the right to stop the interview at any point and can request for their data to be deleted up to three weeks post interview.</li> <li>• Data collected will only be used for the purpose of the current project and future dissemination activities.</li> </ul>



#### 4.6.1.2.

##### **Confidentiality**

*Confidentiality is an important issue for this project, as a small number of participants will be interviewed on sensitive subject matter. In compliance with GDPR principles and the Data protection act:*

- All data (including sensitive and pseudonymised) will be saved on the lead researchers UEL OneDrive for business account, accessible only to the lead researcher through a password protected account using Multi-Factor authentication.
- Written consent will be obtained from participants for collection, storage, archiving and sharing of anonymised data (see above)
- Data will only be used for the purposes it was obtained, will not be retained longer than necessary (recordings will be deleted following transcription, other information will be kept only for the duration of the project)
- The minimum amount of personal information will be collected.
- Anonymising voices and video consent is not feasible, so data will be de-identified upon transcription and recordings will be deleted. The majority of the data will be pseudonymised transcriptions. This data will be saved alongside a participant number so it can be identified if necessary (eg. if the participant requests to withdraw their data).
- Transcripts will be stored separately from the pseudonymisation log preserved to re-identify participants if necessary (see storage and back-up section)

#### 4.6.1.3.

##### **Risk and Safety Measures**

*It is recognised that discussion of the subject of trauma may bring up difficult emotions for participants. Additionally, questions may lead them to reflect on experiences of managing or witnessing high levels of distress in the individuals they support and/or behaviour that challenges which can be linked to vicarious trauma.*

To address this:

- Participants will be informed they can pause or terminate the interview at any time
- The interviewer will remain vigilant for signs of distress and will offer to pause or terminate the interview if distress is observed.

	<ul style="list-style-type: none"> <li>• A debrief follow up call will be offered at the end of every interview</li> <li>• A debrief document will be provided containing signposting information for relevant support services.</li> </ul>
Identify any copyright and Intellectual Property Rights issues and how these will be managed	N/A
<b>Storage and Backup</b>	
How will the data be stored and backed up during the research?	<ul style="list-style-type: none"> <li>• All data will be stored on the UEL Microsoft OneDrive for business aside from MS teams video recordings which will be stored by default on the UEL Microsoft OneDrive for business of the lead researcher, who will be conducting the interview. Recordings will be deleted as soon as they have been transcribed and checked for accuracy.</li> <li>• Total data size is not expected to exceed the UEL personal OneDrive allowance.</li> <li>• The researchers UEL OneDrive for business will contain a 'Thesis' folder, divided into two separate folders to separate pseudonymised data from identifiable data: <ol style="list-style-type: none"> <li>1. A folder titled 'Sensitive Data' will contain Spreadsheet 1 and 2, containing identifiable information including contact information and basic demographic information.</li> <li>2. A folder titled 'Project' will contain pseudonymised data including interview transcripts, analysis and project write up.</li> </ol> </li> </ul>
How will you manage access and security?	<ul style="list-style-type: none"> <li>• The lead researcher will have sole access to identifiable data</li> <li>• All data (including sensitive and pseudonymised) will be saved on the lead researchers UEL OneDrive for business account, accessible only to the lead researcher through a password protected account using Multi-Factor authentication.</li> <li>• Interview recordings will be deleted following transcription.</li> <li>• Pseudonymised data (eg. transcripts and analysis) will be shared only with the research supervisor through UEL OneDrive for Business</li> </ul>

<b>Data Sharing</b>	
How will you share the data?	<ul style="list-style-type: none"> <li>• Only anonymised/pseudonymised data will be shared</li> <li>• Anonymised transcribed data alongside job role (eg. support worker/senior support worker/team leader) will be included in the final project write up. The final project write up will be shared through UEL's research repository.</li> <li>• Extracts of anonymised transcribed data may be included in dissemination of the project, eg. in presentations.</li> </ul>
Are any restrictions on data sharing required?	<ul style="list-style-type: none"> <li>• Only anonymised/pseudonymised data will be shared</li> <li>• Sensitive or identifiable data will only be accessible by the lead researcher and will not be shared</li> </ul>
<b>Selection and Preservation</b>	
Which data are of long-term value and should be retained, shared, and/or preserved?	<ul style="list-style-type: none"> <li>• The log which contains data that could re-identify the participants will be deleted upon completion of the project</li> <li>• Pseudonymised data (eg. transcripts and analysis) will be stored for three years for dissemination purposes</li> </ul> <p>4.6.1.4.</p>
What is the long-term preservation plan for the data?	<ul style="list-style-type: none"> <li>• Data of long-term value will be shared with the research supervisor through UEL OneDrive for Business.</li> <li>• The final project write up will be shared through UEL's research repository.</li> </ul>
<b>Responsibilities and Resources</b>	
Who will be responsible for data management?	<ul style="list-style-type: none"> <li>• Merry Wright (Lead Researcher)</li> <li>• Dr. Paula Corredor-Lopez (Research Supervisor)</li> </ul>
What resources will you require to deliver your plan?	UEL Microsoft 365 suite including OneDrive for Business.

<b>Review</b>	
	<p>Please send your plan to <a href="mailto:researchdata@uel.ac.uk">researchdata@uel.ac.uk</a></p> <p><b>We will review within 5 working days and request further information or amendments as required before signing</b></p>
Date: 03/05/2022	<p>Reviewer name: Penny Jackson Assistant Librarian (Research Data Management)</p>

## Guidance

Brief information to help answer each section is below. Aim to be specific and concise.

For assistance in writing your data management plan, or with research data management more generally, please contact: [researchdata@uel.ac.uk](mailto:researchdata@uel.ac.uk)

### Administrative Data

#### Related Policies

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

#### Data collection

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

#### Documentation and Metadata

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

#### Ethics and Intellectual Property

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

#### Storage and Backup

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

#### Data Sharing

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

#### Selection and Preservation

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository (<https://repository.uel.ac.uk>) or a subject repository. How long should data be retained?

## APPENDIX I: Debrief Form



### PARTICIPANT DEBRIEF SHEET

#### **Exploring residential support workers insight into supporting young people with learning disabilities who have experienced trauma.**

Thank you for participating in my research study on supporting young people with learning disabilities who have experienced challenging and/or traumatic life events. This document offers information that may be relevant in light of you having now taken part.

#### **How will my data be managed?**

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

#### **What will happen to the results of the research?**

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository. Findings will also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks, magazine articles, blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally. Any personally identifying information will be removed.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised research data will be securely stored by Dr. Paula Corredor-Lopez for a maximum of 3 years, following which all data will be deleted.

### **What if I been adversely affected by taking part?**

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support:

- The Samaritans: 116 123.
- Support through local Mind services <https://www.mind.org.uk/about-us/local-minds/>
- Speak to your General Practitioner (GP) for referral to your local mental health service
- Mental health and wellbeing apps:
  - Headspace
  - Unmind
  - Sleepio

**Who  
can I**

### **contact if I have any questions/concerns?**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Merry Wright  
U2075235@UEL.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr. Paula Corredor-Lopez. School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: P.Corredor-lopez@uel.ac.uk

**or**

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Email: t.patel@uel.ac.uk)

**Thank you for taking part in my study**

## APPENDIX J: Interview Schedule

- How much do you know about the histories of the young people you work with?
  - Would it be helpful to know more?
- Many young people with LD go through difficult life experiences (eg. they might have been in foster care, been neglected, bullied or abused in some other way). If a young person you work with has been through difficult life experiences when they were younger, can you describe how that might effect them?

Prompts:

- Behaviour?
- Relationships?
- Wellbeing?

- How do you currently support young people who have been through difficult life experiences?

Prompts:

- When they are struggling in some way?
- When they seem distressed?
- How do you support them emotionally?
- How do you make them feel safe?

- Can you tell me about anything you would like to do differently?
- How does your service enable you to support these young people?
- Is there anything else they could do?
- What could services do differently to support young people with LD who have had difficult life experiences?
- How does it feel for you to support young people who have been through difficult life experiences?

*'Trauma' is used to describe both one-off events and things that are experienced over months or years, for example within a young person's family or peer relationships. A traumatic experience often involves a threat to a young person's physical or emotional safety, and a sense of being trapped, powerless or unsupported in the face of a perceived danger or in the time afterwards. (Young Minds, 2021)*

- What is your understanding of this?
- How does this impact the work you do with young people?

## APPENDIX K: Sample Annotated Transcript

Interviewer Extract	Codes
<p>Interviewer: Many young people with learning disabilities, have had difficult life experiences like they might have been in the care system, foster care, they might have been bullied or abused in some other way. So if you're working with a young person, you know they've had some difficult history. Do you have any ideas about how that would affect them or if you noticed anyways that affects them?</p>	
<p>Participant: Sometimes it-it-it does affect them and you could see it by their behaviours and some changes as well...Some of the things they cannot express verbally. Sometimes when you use simple words or pictures as well, sometimes it helps communicate to you as well, because I-I did have a-an encounter with one resident before, a while ago. She she's not- She's verbal, but yet can't express most of the things. So I found it useful to use pictures and in that instance I was able to get through to her and I got a lot information and some of the things she can write as well, which is something people didn't know [laughing] like they knew that she could write, but like expressing herself is about encouraging that- that you could write what you're feeling. And then you got to a point where she was more communicative and she was more like selective mute as well...So she choose when and how to communicate, but with me and... umm...the more rapport, we build, the more I go down to her level to communicate, I was-I, I managed to get a lot of information from her. And this was, I think it was around 2019.</p>	<p>Impact on behaviours</p> <p>Adapting Communication</p> <p>Impact of LD Adapting Communication</p> <p>Supporting child to share</p> <p>Finding out about history from child</p> <p>Being a safe space</p>
<p>Interviewer: So did you get an idea then...It sounds like she disclosed lots of things because you built that trust. Did you get an idea around like how the things that she'd been through had kind of affected her, like in terms of her well-being?</p>	
<p>Participant: Yeah. In terms of mostly-sometimes it's also certain things that triggers her as well, like something that really happened in the past and because</p>	<p>Triggers</p> <p>Direct incidents and trauma response</p>



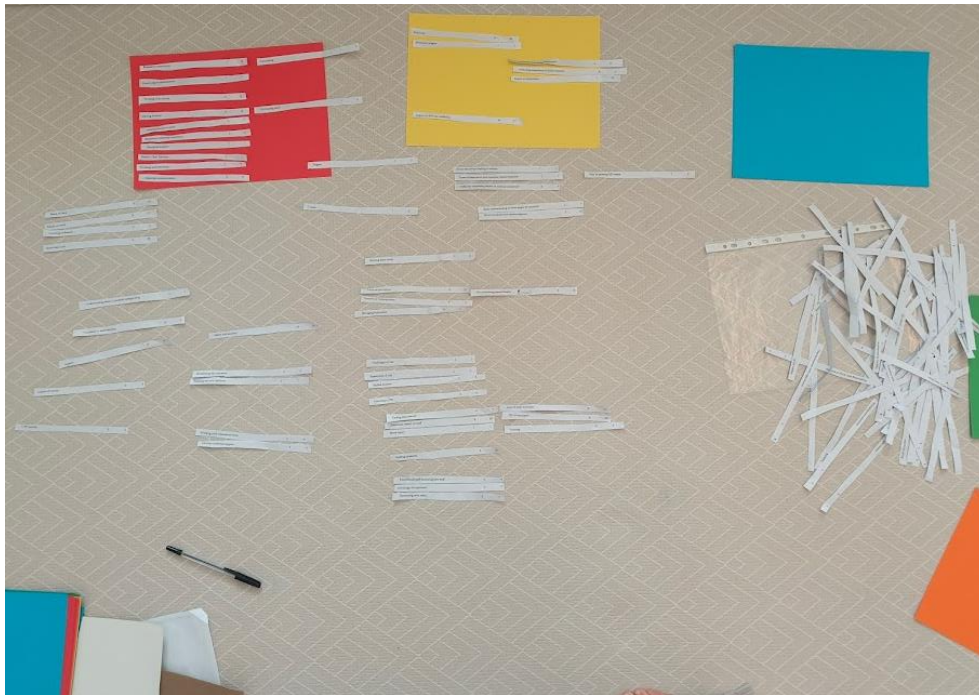
<p>at first we didn't know her that much. But then as time goes on, the more we knew her, the more information as well, she revealed, the more we were able to work around it, but yeah, I think it was...sort of...I don't know how to put it [laughing]. But I think it was helpful knowing a lot a lot more from her as well.</p>	<p>Finding out about history from child          Building a picture as part of support          Time          Value of information</p>
--	--

Interviewer: Yeah, definitely. And do you get a chance? Like, did you get a sense of like how the stuff that she'd been through, how it affected her relationships?

<p>Participant: It was very hard for her to build a relationship with other service users and other staff members as well. She was mostly...how would I say? Attached to me because she felt like I was giving her the time helping her process, also not judging and also taking my time and something...and sometimes I even have to play around just to get her to talk and things like that. So she found that...I think very sort of...confidence. She got a bit of confidence to say, OK, you know what? Let me tell [Participant name] how these things is happening. What has happened and stuff like that. So it was a bit of a challenge at first, but once I get through to her, everything was sort of OK and staff were able to work around her as well.</p>	<p>Impact on relationships          Connecting          Being a safe space          Time          Supporting Child to share          Connecting          Building a picture as part of support</p>
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Interviewer: Yeah, that sounds really...really positive.

## APPENDIX L: Candidate Theme Generation Process





Sense of duty	5	13
Family vs work	8	17
More than a job	5	10
Putting myself in their shoes	2	4
Weight of responsibility	3	4
Rescuer or Protector	3	4
Rewarding role or Motivation for role	9	13
Bringing in the personal	5	6
Role impacting life	5	8
Facing reality of abuse (impacting worldview)	1	2
In it for the right reasons	4	4
Learning to detach	3	4
Managing own emotions	5	9
Reputation of role	1	1
Role impacting status	1	3
Values	1	3

Personal views - Parent?

Family style

More than a job

Safety and security	10	32
Reparative experiences	7	18
Reparative relational experience	5	11
Connecting	8	37
Emotional support	1	1
Working with emotions	2	5
Role of spotting MH needs	2	2
Respect Time Patience	5	7
Adapting communication	5	9
Moving forward	5	8
Moving forward through positive experiences	2	3
Focus on positives	4	8
Being aware of triggers	3	7
Independence	2	2
Developing skills	3	4
Child centred	6	10
Holding trauma in mind	3	3
Preventing retraumatization	1	3
Working with trauma	5	10

*Reparative Experiences*

*Moving forward*

*SW laws system  
↓  
Product of  
Hopelessness*

*Relationship skills to protect against hopelessness: 2*

Disconnection with organization	3	9
Collisions unavoidable	4	5
Feeling disconnected	4	7
Emotional impact on staff	1	1
Moral injury	1	1
SW wellbeing	4	7
Challenges of role	2	2
Stressful role	3	5
Staffing pressures	5	10
Opportunities for activities	5	16
Stigma	2	2
Lack of faith in system	5	12
SW not equipped	6	16
Support from external services	6	8
Quality of training	4	7
Training	3	6
Basic resources	3	3
Meeting basic needs	3	3
Time to support	1	1
Not prioritising mental health	3	5
Engaging services	1	3

*Trauma in the system*

*Disability in the system*

*Dis-abled System*

*Neglected*

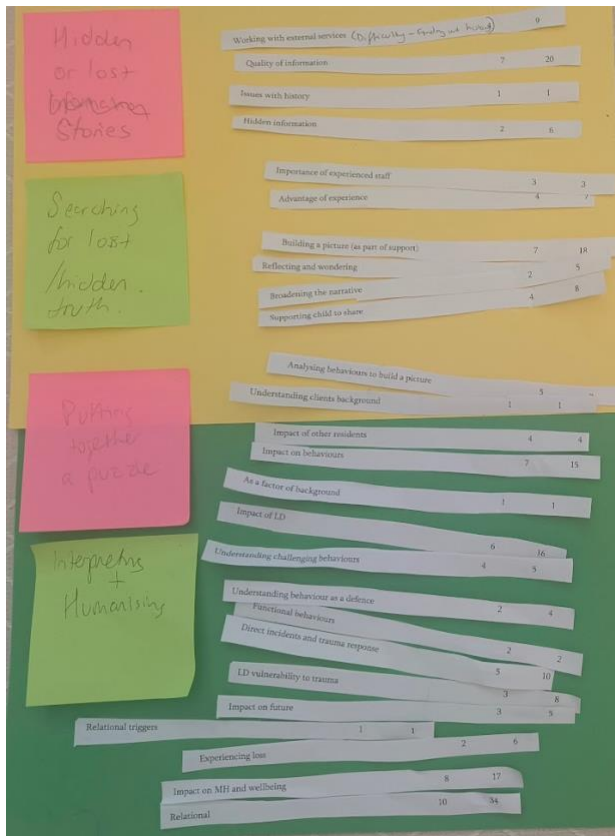
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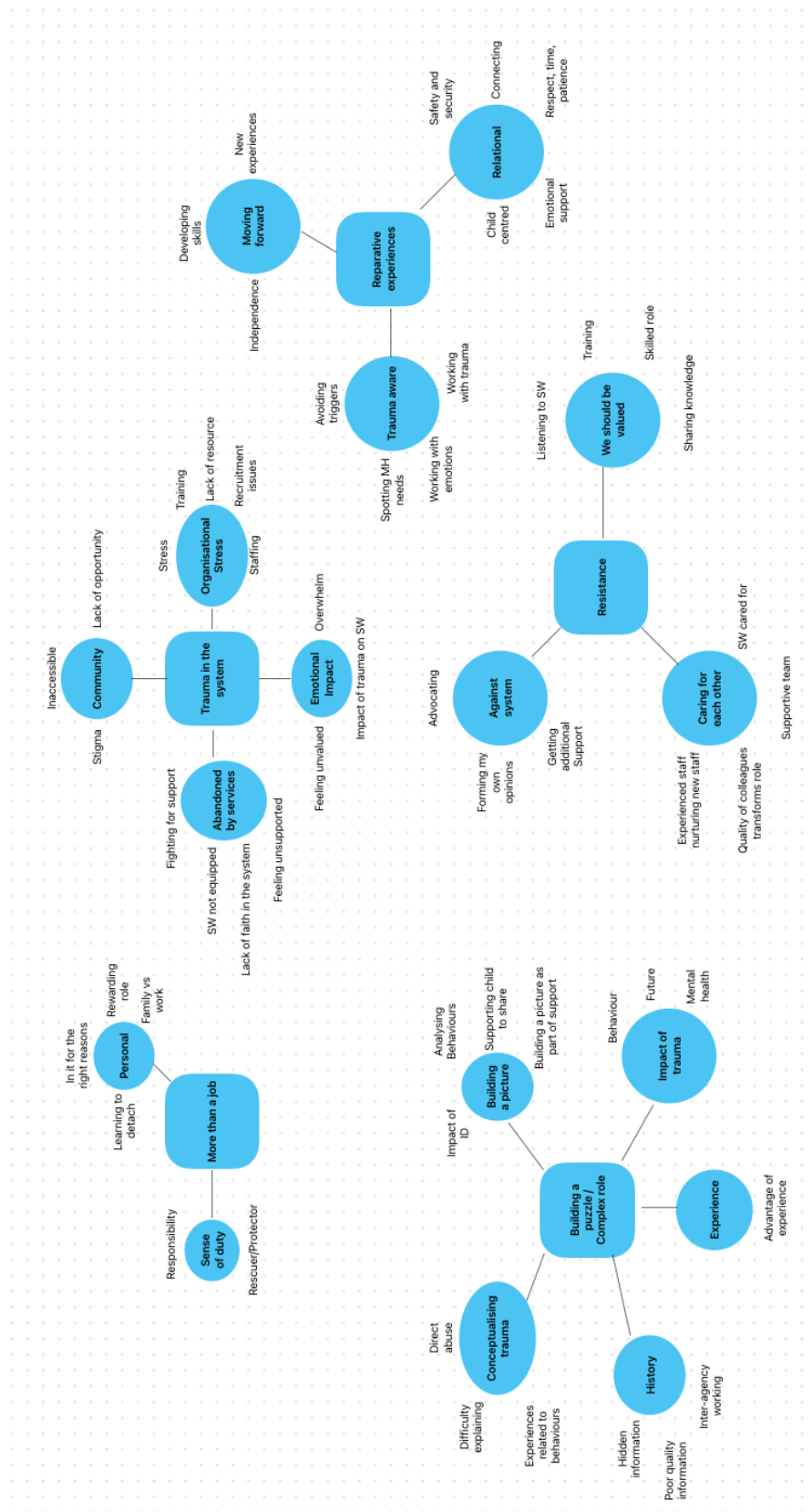


Final candidate themes:

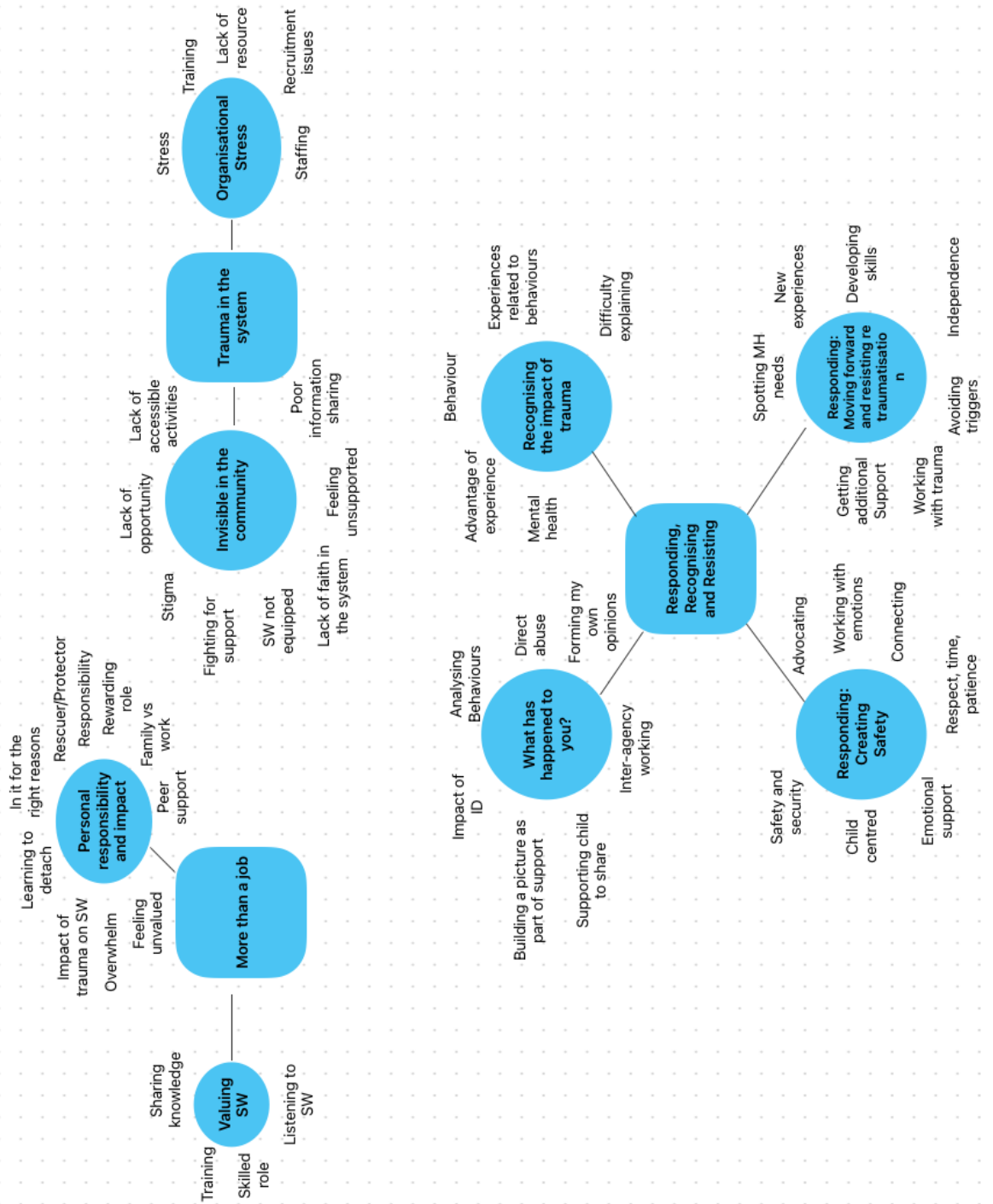


# APPENDIX M: Thematic Maps

## Early thematic maps



Further developed thematic maps:



## APPENDIX N: Title Change Approval



School of Psychology Ethics Committee

### REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for a proposed title change to an ethics application that has been approved by the School of Psychology

By applying for a change of title request, you confirm that in doing so, the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed, then you are required to complete an 'Ethics Application Amendment Form'.

#### How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	Using your UEL email address, email the completed request form along with associated documents to Dr J�r�my Lemoine (School Ethics Committee Member): <a href="mailto:j.lemoine@uel.ac.uk">j.lemoine@uel.ac.uk</a>
4	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.

#### Required documents

A copy of the approval of your initial ethics application.	YES <input checked="" type="checkbox"/>
--	--

#### Details

Name of applicant:	Merry Wright
Programme of study:	Professional Doctorate in Clinical Psychology
Title of research:	Exploring Residential Support Workers Insight into Supporting Young People with Learning Disabilities Who Have Experienced Trauma.



Name of supervisor:	Dr. Paula Corredor-Lopez
<b>Proposed title change</b>	
Briefly outline the nature of your proposed title change in the boxes below	
Old title:	Exploring Residential Support Workers Insight into Supporting Young People with Learning Disabilities Who Have Experienced Trauma.
New title:	Trauma-Informed Care for Young People with Intellectual Disabilities: Perspectives of Residential Support Workers
Rationale:	To better summarise the study in a more succinct way , as agreed at Viva stage.

<b>Confirmation</b>		
Is your supervisor aware of your proposed change of title and in agreement with it?	YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>
Does your change of title impact the process of how you collected your data/conducted your research?	YES <input type="checkbox"/>	NO <input checked="" type="checkbox"/>

<b>Student's signature</b>	
Student: (Typed name to act as signature)	Merry Wright
Date:	19/08/2024

<b>Reviewer's decision</b>		
Title change approved:	YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>
Comments:	Please enter any further comments here	
Reviewer: (Typed name to act as signature)	Miles Thomas	
Date:	20/08/2024	